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| 13. ABSTRACT (Maximum 200 words) The purpose of this study is to add to the scientific basis for providing subacute care in the home, by testing the effects of an immediate post-operative intervention designed to facilitate quality of life as well as physical and psychological well-being after diagnosis and surgery for breast cancer. A 2-group randomized clinical trial with repeated measures will examine the effects of the intervention. The control group (n=100) will receive customary medical care. The intervention group (n=100) will receive individual physical and psychological support in the home through 2 telephone calls and 2 in-home visits from a registered nurse within the first 14 post-operative days. To participate in the study, a woman must be at least 21 years of age, be scheduled for breast cancer surgery and, ultimately, discharged from the hospital within 48 hours. Data collection for both groups occurs at recruitment prior to surgery and again at 4 weeks post-surgery before beginning adjuvant therapy. Between group comparisons of quality of life, physical and psychological well-being will be made. We hypothesize that, compared to the control group, recipients of the intervention will report 1) higher quality of life, 2) fewer surgical wound complications, 3) higher physical functioning, 4) lower anxiety levels, 5) fewer physical symptoms, and 6) lower out-of-pocket expenses associated with health care during the intervention period. While data is still too limited for statistical analysis, both physicians and intervention participants report anecdotally that they are pleased with the outcomes of the study, e.g., lower anxiety and comprehensive post-surgical education. | | | | | |
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FOREWORD

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A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

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A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

INTRODUCTION

I. Subject of Grant

The **subject** of this grant is the provision of a cost effective, highly targeted, randomized clinical trial (intervention) which provides post-surgical nursing care in the home for women following short-stay surgery for breast cancer.

II. Purpose of Grant

This study is designed to address the well-documented, but unmet, physical and psychological needs of women undergoing surgery for breast cancer.^{1,2,3,4} The **purpose** of this study is to support women during the immediate post-operative phase in order to facilitate higher quality of life, physical and psychological well-being following surgery for breast cancer at a reasonable cost.

III. Scope of Research

The **scope** of this study is to test the impact of a short-term (14 days post-surgical), subacute care intervention for women (21 years of age and older) who have undergone short-stay surgery (48-hours or less) for breast cancer. When compared to conventional short-stay surgical care, the subacute care in-home intervention is targeted to help women attain optimal recovery during their immediate post-surgical phase and assist them in regaining their pre-surgical health status prior to initiating adjuvant therapy. The broader impact of this study may include contributions to policy on length of stay for breast cancer surgery, post-surgical nursing care needs, and standardizing customary costs for care.

The technical objectives of the study are to:

- A. Test the effects of a nursing intervention consisting of immediate post-operative (1-14 days) telephone and in-home nursing assessment and care, by describing and comparing the physical and psychological well-being between 2 groups of women with breast cancer: the intervention group, who receive a 14 day treatment (nursing care in the home and phone contacts) consisting of individual physical and psychological support, self-care, and education; and the control group, who receive conventional post-surgical medical care.
- B. Compare intervention and control group perceptions on the dimensions of physical functioning, anxiety status, quality of life, and self-care knowledge.
- C. Compare the control and intervention groups' out-of-pocket expenses which are sustained by the women and their families in relation to the breast surgery, costs of treatment,

and related services during the first month post-hospital discharge. Further comparisons are being made on the overall financial impact of the illness and surgery on family finances, e.g., savings, employment, income, etc. Along with commonly occurring out-of-pocket costs, the analysis includes an assessment of the types and costs of complementary (alternative) therapies used by both groups to treat cancer.

IV. Background of Previous Work

Since 1991, the principal investigator has studied the quality of life of long-term female cancer survivors and newly diagnosed mid-life and older women with cancer, receiving funds from the Oncology Nursing Society, Michigan State University (MSU) College of Nursing, and the American Cancer Society (through an institutional grant to the MSU Cancer Center). Each study has examined the needs of women with cancer (most commonly breast cancer) and their expressed concerns through the course of their disease and return to productivity. This research allows for an expansion of these initial findings by instituting a program of subacute care that incorporates previously identified needs of women with cancer.

A pilot study (conducted by Wyatt in 1995) of 18 female breast cancer survivors revealed that in the 2 weeks following breast surgery women experienced multiple symptoms, both physical and psychological.⁵ Participants were recruited from physicians' offices and from support groups for breast cancer survivors. They ranged in age from 30 to 83, with a mean age of 50. Twelve had completed at least some college or trade school, and all had finished high school. All respondents were white, 16 were married, and 2 were divorced. A majority of respondents (N=11) had spent two or more days in the hospital following surgery.

Reflecting on the two weeks immediately post-operative, more than half of the participants reported experiencing physical symptoms directly related to the surgery. The symptoms were tenderness (N=15), swelling (N=12), excess drainage (N=13), pain (N=16) with a mean pain rating of 6.19 on a 10-point scale with 1 being least painful and 10 being most painful, tingling (N=12), lack of sensation (N=8), and tightness in the chest wall (N=11). Further, at least half of the women experienced psychological symptoms such as, trouble sleeping (N=10), fatigue (N=15), inability to concentrate (N=14), weakness (N=14), numbness (N=17), waking in the night to urinate (N=11), lack of interest in sex (N=11), and mood swings (N=9). All participants reported some area of decreased ability to engage in physical functioning through daily activities. The most frequently reported difficulties were with moderate activities, such as moving a table and strenuous activities, such as lifting a heavy object, carrying groceries, climbing more than one flight of stairs, or walking several blocks. Finally, psychological distress was a common factor among the participants (N=16). The most commonly reported problems were feeling that "everything is an effort," that "life is a failure," that they were "fearful about the future," and that they were "happy" only some of the time. Despite the considerable range of negative effects after breast cancer surgery, respondents reported scarce use of resources outside of their families for health care. Most common were follow-up visits to their surgeon by 15 women. They averaged 2.5 visits, with a range of 0 to 10 in the two weeks following surgery. Other services used by participants included their primary physician (N=2), additional hospital admissions (N=3), emergency room visits (N=2), housekeeping service (N=1), transportation assistance (N=2), and

psychologist (N=2). A variety of needs experienced by these women in the 2 weeks following breast cancer surgery appeared to be unmet. This is despite an average hospital stay of 2.86 days. With earlier discharges this problem will exacerbate, and the health care system must ensure that patient's needs are met in the home or through outpatient and ambulatory care.

The need for subacute nursing care interventions among women newly diagnosed with breast cancer has been further highlighted by results from focus groups conducted by Co-Principal Investigators on this DoD grant, Given and Given.⁶ The 30 women who participated were unanimous in pressing for transition care to include a patient advocate during the initial treatment for cancer who could: provide information, assist with symptom management, present exercise regimens to improve upper body functioning, suggest community resources, and communicate a plan for continuity of care between physicians and women. The women wanted to know about resources for questions regarding radiation and chemotherapy, and a regular source to contact with their questions.

In a study entitled, "Quality of Life of Long-Term Female Cancer Survivors" funded by the Oncology Nursing Society in 1992, Wyatt found that women with breast cancer perceived a need for greater support during the immediate post-surgery transition phase when they had many physical and psychological issues to confront.⁷ While long-term survivors resolved many of their own issues, they believed they could have regained productivity sooner with transition care that included information and support for physical and psychological well-being. Respondents suggested the need for a trajectory of care with significant emphasis on the post-surgery, pre-adjuvant therapy period.

The Co-Principal Investigators of this research team, Given and Given, have been engaged in the following ten funded research projects: Caregiver Responses to Managing Elderly Patients at Home, NIA (#R01 AGO6584), 1986-1988, 1989-1993; Family Homecare for Cancer--A Community-Based Model, NINR and NCI (#R01 NR01915), 1989-1991, 1993-1997; Family Homecare for Cancer Patients, ACS (#PBR-32A), 1988-1990; Impact of Alzheimer's Disease on Family Caregivers, NIMH (#1 R01 MH41766), 1987-88 and 1989-1991; Costs of Cancer Care to Patients and Families, NCI Contract DHHS P.O.#263-MD-101487-1; Rural Partnership Linkage for Cancer Care, NCI (#1 R01 CA56338), 1992-1998; Cancer Prevention, Outreach and Access to Care for the State of Michigan, Department of Community Health (State of Michigan), 1996-1997; Cancer Care Intervention to Improve Functioning and Psychosocial Outcomes in Newly Diagnosed Cancer Patients and their Families, Walther Cancer Institute, 1996-1998; and Care, Prevention, Outreach and Cancer Control (Supportive Care) for Cancer Patients, Department of Community Health (State of Michigan), 1997-1998. This research program uses longitudinal designs and community-based clinical trials to address a set of principal themes: 1) the changes in functioning and needs for home care, 2) the social, psychological, physical, and financial impact of these dependencies upon the families who provide care, and 3) women's use of community services to sustain home care.

In a study funded by the American Cancer Society Institutional Grants Program in 1994 entitled, "Quality of Life of Midlife and Older Women Following Breast Cancer Surgery", Wyatt

interviewed 48 women with breast cancer.⁸ The research revealed that women in higher income brackets recovered physical functioning more quickly than their lower income counterparts. One explanation for this finding is that higher income women are better able to pay for services to speed their recovery. An earlier transition back to pre-surgery productivity may be the longer-term benefit of additional assistance during the acute post-surgery time period.

Negative financial consequences have been documented by Given and Given (Family Homecare for Cancer: A Community Based Model #RO1 NR01915) in a summary of preliminary data post-discharge (compiled by Wyatt in 1994) following breast cancer surgery from older women who were newly diagnosed with cancer.⁹ From a total of 24 cases, 6 had outpatient surgery, 7 women had one-day surgery, 5 were hospitalized for two nights after surgery, and another 5 women were hospitalized for three or more nights. Fourteen of the 24 women became heavily reliant upon a family member for care as a substitute for formal care, resulting in cost shifting from the health care system to the family. For example, one woman was forced to move in with her sister, whereas four others had a female family member move into their home post-surgery. One woman not only had no one to care for her, but her husband required care as well. This participant was forced to be a caregiver as well as a patient. Even though the majority of women had a family member to assist them, two had a total of eight visits from a visiting nurse service (VNS) for additional wound care, two needed community services for transportation to medical appointments, and one needed 50 visits from a home health aide in the first 3 months after surgery. One woman used a VNS six times because there was no one to help her. Another woman used a housekeeping service two times in the three months following surgery; she also did not have a regular family caregiver. Eight of the women had to return to their primary care physician (total of 14 visits) within the first three months following surgery for complications related to their cancer, 22 returned to their surgeon for wound care (total of 75 visits), and there was one urgent care visit for pneumonia two weeks after surgery. Self-reported out-of-pocket expenses for 16 women totaled \$7,274 (\bar{x} \$454.63) in the 4 weeks following surgery, while six women had no expenses and two did not know.

This program of research is critical in order to keep pace with rapidly changing health care systems which deliver care to women with breast cancer. The experience of the Principal Investigator of this project is complimented by the expertise of two other well-established cancer investigators (Given & Given).

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

BODY

I. Statement of Work (As Submitted with Original Proposal)

| TASK | TIME PERIOD | ACTIVITIES |
|-------------|--|---|
| Task 1 | Prefunding Period (following notification of funding) | Orient physicians to study at all sites. |
| Task 2 | Months 1 - 6 | Clear IRBs of all agencies. Recruit and train research personnel. |
| Task 3 | Months 7 -12 | Begin participant recruitment, intervention, and data collection. (n=25) |
| Task 4 | Months 13 - 18 | Continue participant recruitment, intervention, and data collection. Monitor accrual. (n=50) |
| Task 5 | Months 19 - 24 | Continue participant recruitment, intervention, and data collection. Monitor accrual. (n=50) |
| Task 6 | Months 25 - 30 | Complete participant recruitment, intervention, and data collection. Begin data entry. (n=50) |
| Task 7 | Months 31 - 36 | Continuing recruitment, intervention, and data collection. Accelerate recruitment if necessary to account for any participants who do not complete intervention. (n=50) |
| Task 8 | Months 37 - 42 | Complete recruitment if needed (n=25). Complete data entry on computer. Begin preliminary data analysis. |
| Task 9 | Months 43 - 48 | Complete statistical analysis. Prepare research reports. Prepare manuscript for publication. |

A. Task 1, Prefunding Period, Orient physicians to study at all sites.

Notification of funding occurred approximately September 1, 1996 and funding began September 15, 1996. There was minimal opportunity to begin this activity during the prefunding period. Physician orientation was moved to the time period for Task 2 (month 1 through 6).

The Principal Investigator and one Co-Principal Investigator initially introduced the study to surgeons at a meeting following surgical grand rounds. An information packet containing the study design, abstract, brochure, consent form, and a letter of agreement between the study and the surgeon was distributed to each surgeon. Within a few weeks following this meeting, the Principal Investigator and a study nurse met with each surgeon individually to describe the study and to explain the potential benefits to his/her patients. At the conclusion of each meeting, the surgeon was asked to sign the letter of agreement (see **Appendix H**) between the study and him/herself. The agreement outlines the protocol to be followed with the intervention participants, and explains that women who meet the study criteria have a 50-50 chance of receiving the intervention. Each surgeon was also informed that he/she would receive two reports (see **Appendix J**), an interim (at approximately 7 days post-operatively) and final (at 14 days post-operatively), for each of his/her patients in the intervention arm of the study. Surgeons were also informed that hospital/office charts of intervention participants would be labeled so they will know which patients are in the intervention arm of the study. Currently, eleven surgeons are participating in the study.

B. Task 2, Months 1-6, Clear IRBs of all agencies. Recruit and train research personnel.

IRBs were cleared between September 1996 and May 1997. Our five sites were cleared respectively September 1996, January 1997, March 1997, April 1997, and May 1997. SPAs were submitted and approved for each site as IRBs were obtained. IRB and SPA activity is complete. We will maintain current IRBs through annual renewals.

While our five sites are providing adequate recruitment, we may include additional sites during year two if needed to maintain accrual of participants. We have letters of agreement with three additional sites. These sites will be activated by obtaining IRB and SPA approvals if at any time they are needed to maintain participant recruitment goals.

Research personnel have been hired and oriented. They are fully functional in their roles at this time. Intervention nurses have been hired and oriented to accommodate the number of participants currently in protocol.

C. Additional Activities, months 1 - 6.

In addition to the Statement of Work tasks, the following materials and procedures have also been developed and implemented:

1. Policy and Procedure Guidelines: Detailed guidelines have been prepared to provide consistency across the key activities of the study (i.e., *recruitment, intervention, interview, chart audit, and quality assurance*).

a. Recruitment guidelines include the position description for recruiters, randomization procedure instructions, detailed instructions for the recruitment of patients and obtaining consent, pre-test questionnaires, agency consent forms, communications guidelines for interactions with agencies and patients, instructions for computerized entry (Paradox Program) of recruitment data, study brochure, and recruitment resources.

b. Intervention guidelines include a professional nursing overview, the position description for intervention nurses, information regarding confidentiality, universal precaution guidelines, health care referral policy, and attrition information.

c. Interview guidelines include an interviewer training module, guidelines for conducting interviews, instructions for completing paper documentation (forms and letters), and instructions for the Computerized Interview Version 3 (Ci3) data entry program.

d. Chart Audit guidelines provide detailed instructions on obtaining diagnosis and treatment information from patients' medical charts.

e. Quality Assurance (QA) guidelines include directions for QA review of recruitment, intervention, interview, and chart audit materials.

2. Intervention Protocol: Intervention protocol and documentation guidelines have been created and standardized via customized computerized entry (Paradox). A standardized protocol for our 14 day nursing intervention is in place. Documentation of the protocol is entered on a paper chart (see **Appendix L**) immediately following each intervention encounter. At the conclusion of the fourteen day protocol, the nurse enters her paper chart into our customized, computerized data program (Paradox). The individual pages of the paper chart mirror the individual screens of the computerized data entry screens. Once nurses become familiar with the paper chart, our goal is to assist the nurse in the transition to direct data entry (immediately following each protocol encounter) into the computerized program. The computerized data entry program allows continual access to summary information such as most frequently assessed symptoms, most frequently occurring nursing diagnosis, and most frequently used nursing interventions. All computerized data are backed up daily.

3. Data Collection Protocol: The data collection tools have been computerized on a Ci3 software program and are fully operational. **Pre-test** data, which is collected prior to surgery via self-administered paper copy (see **Appendix I**), is entered into our Ci3

program immediately following collection at recruitment. **Post-test** data collection is conducted via telephone interview, and is entered directly into our Ci3 program as the interview is conducted. The initial few interviews were collected via telephone, but were recorded on paper copies (see **Appendix N**) while preparing the customized computerized program. Currently, all interviews are entered directly into our computerized program without a paper copy step. All computerized data are backed up daily.

4. Chart Audit Protocol: Basic chart data are collected via paper copy and then entered into our computerized program (Ci3). While not part of the original proposal, we are currently developing a new computer-based program in Ci3 to track post-protocol complications which occur for both control and intervention participants.

5. Quality Assurance Protocol: The quality assurance programs for recruitment activities, intervention protocol, and interview data entry are in place. Both research staff and the Principal Investigator (P.I.) participate in quality assurance reviews on a regular basis. The P.I. reviews weekly recruitment reports. The P.I. also conducts a complete QA on protocol entries for every tenth intervention participant (in the Paradox computerized program). In addition, the P.I. spot checks multiple Paradox entries. Finally, the P.I. reviews a complete audio taped versions of every tenth telephone interview (post-test).

D. Task 3, Months 7-12, Begin participant recruitment/intervention/data collection (n=25).

To date, our anticipated n=25 has been exceeded. We currently have n=30 recruited into the study. Recruitment and intervention protocols are in full operation. Post-test interviews have been completed on n=25.

II. Experimental Methods

A. Design (please see Figure 1)

A 2-group randomized controlled clinical trial with repeated measures is examining the effects of a short term intervention consisting of the combination of a telephone and in-home intervention. The intervention lasts 14 days and focuses on physical and psychological subacute care following short-stay breast cancer surgery. Participants are randomly assigned to the intervention or control group. The intervention group receives the telephone and in-home study protocol; the control group receives conventional post-surgical medical care.

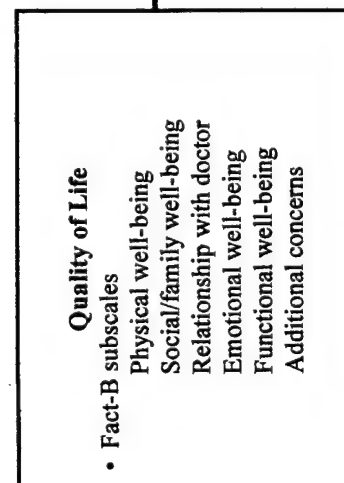
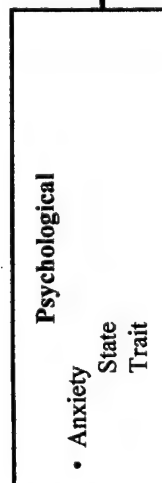
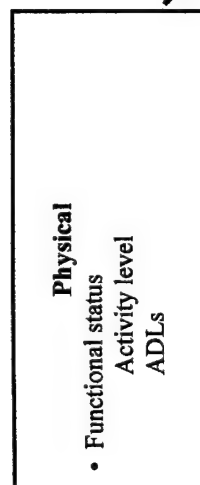
Data are collected from all women 2 times over a period of 1 month (at recruitment and four weeks post-surgery). Data collection is through a combination of self-administered written questionnaires and telephone interviews. The rationale for this schedule is to obtain baseline data and to compare them with data collected after the intervention. This allows us to assess the immediate efficacy of the intervention.



STUDY DESIGN - A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

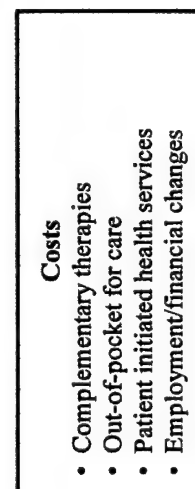
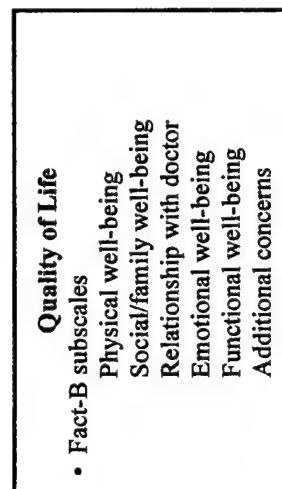
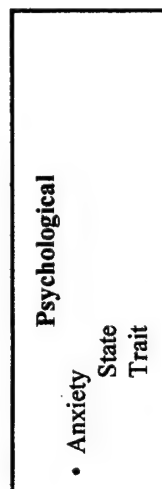
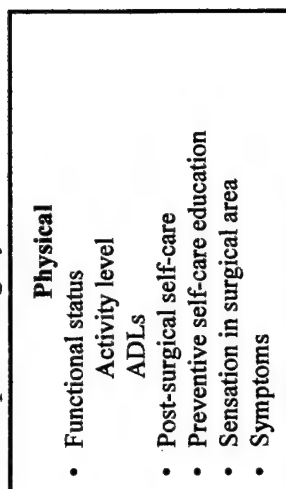
Pre-test

Self-administered instruments at pre-surgical recruitment



Post-test

Telephone interview at 4 weeks post-surgery



Post-Operative Weeks 1 and 2

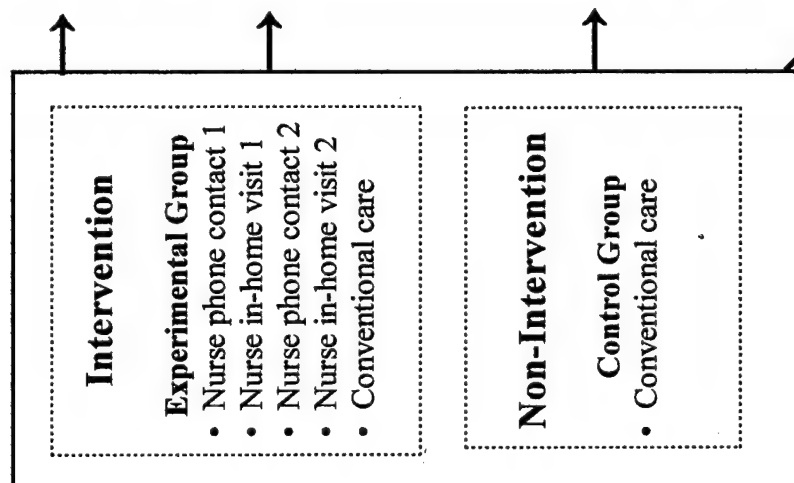


FIGURE 1

B. Sample

Participants are women age 21 and older admitted for short-stay surgery (48 hours or less), as first treatment for breast cancer, who are able to speak and read English. For this study, surgery refers to mastectomy with lymph node dissection, mastectomy without lymph node dissection, or lumpectomy with lymph node dissection. Exclusionary criteria are pregnancy, in situ tumors, reconstructive surgery concurrent with removal of cancerous tissue, an acute episode of medically diagnosed mental illness at the time of current breast cancer diagnosis, and a home address of more than 40 miles away from the surgeon's office. Most women are stage I or II since women with these stages generally undergo surgery as their initial treatment. English speaking skill is necessary to ensure that directions related to the data instruments and protocol teaching are understood. A total of 200 participants are targeted for inclusion during the grant period.

C. Recruitment

Eleven surgeons are currently providing potential recruits to the study. A target goal of ten participants per month has been set to meet the study's accrual objective of the grant. This recruitment goal allows for decreased accrual through winter holiday times and summer vacation periods. Further, additional surgeons will be invited to participate in the study during years two and three in order to meet our accrual goals.

To assist in recruitment, a study brochure was prepared (in lay language) and is distributed to each potential recruit. This brochure (see **Appendix G**) outlines each participant's 50-50 chance of being assigned to the intervention group of the study, discusses the intervention protocol, describes benefits of being in the control group, and explains how participation contributes to breast cancer knowledge overall.

Several recruitment issues have been noted during year one of the study. First, women are typically informed of their diagnosis and scheduled for surgery within a matter of days. The short window of time between confirmed diagnosis and surgery requires close communication between the study recruiter and the surgeon's office staff in order to identify potential participants in a timely manner. Secondly, the short time frame limits the number of opportunities to meet with women face-to-face once they are identified. Thirdly, we have found the recruitment process to be much more labor-intensive than originally expected. When face-to-face contact between recruiter and potential participants is not possible, participants are contacted over the phone, given a brief summary of the study, and asked whether they would like additional information sent to their home. A follow-up phone call is then made to confirm that the materials have been received and to answer any questions the patient may have. If there is not enough time to mail the materials before surgery, the recruiter will arrange to visit the potential participant at home to deliver the pre-test questionnaire and consent form personally. Despite these potential obstacles during recruitment, accrual is proceeding on schedule.

D. Accrual

Actual accrual of participants has been successful despite the short window of time between diagnosis and surgery. Ninety-six percent of women contacted have been successfully accrued and our attrition rate is zero. We attribute the success of accrual to the fact that all study recruiters are registered nurses who are well informed about breast cancer, the surgical process and other health issues about which women may have questions. Recruiters are also instructed to consider the psycho-social issues facing cancer patients and employ empathy and active listening during recruitment.

E. Randomization

Once accrued and baseline data are collected, women are randomly assigned to the intervention or control groups. The recruiter telephones the central research office, where a research assistant selects the next randomized card. The research assistant provides the recruiter (intervention group only) with the name of the nurse intervenor assigned to this participant. To date, the randomization procedure is working well.

F. Control Group

Conventional post-operative care is provided by their surgeon following surgery. At the conclusion of participation in the study (3 to 5 weeks post-surgery), this group receives a resource packet that the intervention group received during their participation, and they receive a \$10 check for contributing to the study.

G. Intervention Group

The subacute care intervention is accomplished through a minimum of four contacts (two phone contacts and two home visits) by a nurse intervenor. The first phone contact is made within the first post-discharge day to assess any immediate needs and to schedule the first home visit. The first visit focuses on **physical** issues related to surgery, symptoms, dressing, drain, and quality of life assessment. The second phone contact occurs between the first and second in-home visits to provide an ongoing link to the health care system, assess physical and psychological needs, and to schedule the second visit. Women are also encouraged to contact their intervention nurse between visits if needs or questions arise. At the second visit, the intervention focuses upon **psychological** issues, provides follow-up on physical concerns and education regarding breast self exam, range-of-motion arm exercises, and lymphedema prevention. Information on community resources is also provided with the goal of increasing access to opportunities for ongoing support.

Finally, one or two additional phone contacts or visits by the nurse intervenor are sometimes necessary during the two week period following surgery to ensure a timely return to pre-surgical activities.

H. Intervention Protocol

While the protocol consists of a minimum of two telephone calls and two in-home visits for each woman in the intervention arm of the study, some women may receive additional encounters if assessed as necessary by the home care nurse. All protocol steps are covered by

the nurse during the first fourteen post-operative days in the participant's home. Please see **Appendix K** for our detailed protocol and computer entry documentation information.

Most women have required more than the minimum protocol due to uncertainty of drain management and, in particular, clogged drainage tubing. Additional concerns have included symptom management, i.e., pain, constipation, and fatigue. Emotionally, women are experiencing post-surgical anxiety often associated with awaiting their lymph node status reports. This anxiety further compromises their overall quality of life. Therefore, in order to decrease return visits to the health care system, our nurse intervenors have made additional visits and contacts to assist with the management of these concerns. Additional phone calls often provide adequate information for the participant to manage her symptom or concern independently. Please see the "Results Section" for details on the protocol encounters.

I. Data Collection (please see Table 1)

Data are collected at 2 points over a four week period: at entry into the study (baseline), and at 4 weeks post-surgery. Baseline data are collected from all participants at the time of recruitment and prior to randomization. Once the nurse intervenor completes the intervention with a participant, she contacts the research office so the participant can be assigned to an interviewer for the data collection which occurs four weeks after surgery.

The 4-week data collection occurs after the completion of the intervention and prior to re-entry into the formal health care system for adjuvant therapy. These 4-week data provide information on the immediate effectiveness of the intervention. Clinical measures, related to stage of disease, etc., is obtained through chart review.

In some cases, women are referred for chemotherapy as early as three weeks post-surgically. We have allowed for a variation of one week before or after the standard four week data collection point, which allows for a range between three to five weeks post-surgery for the interview to be conducted. In most cases, this added flexibility to our interview time frame allows us to conduct the post-test interview prior to the women commencing adjuvant therapy. However, we have had two cases in which the interview was conducted during the same week that chemotherapy was initiated. These situations included not only the early commencement of chemotherapy, but also personal issues in the participant's lives, i.e., a marital separation. Other variations included one woman who preferred to do the interview in person prior to a clinic appointment due to being hard of hearing. Overall, the vast majority of participants have been able to comply with our standard interview schedule.

J. Data Analysis

1. Baseline evaluation. Frequency distributions and measures of central tendency and variability are being calculated for all variables of interest. The variables can be grouped into four broad categories as 1) Physical; 2) Psychological; 3) Quality of Life; and 4) Costs. Once we have adequate data to conduct statistical analysis, several measures will be evaluated on each of these categories. Adjustments in the alpha level, which depends on the total number of statistical tests using the same data, will be made with the

Bonferroni method to control for type I errors¹⁰. The baseline comparisons will be done to evaluate if the two groups are the same on demographic and other variables that could impact on the outcome variables to be evaluated post-intervention. If differences between groups are observed despite randomization, these variables will be treated as covariates in final our post-intervention analyses. For all continuous variables, two-way analysis of variance (ANOVA) will be used at baseline, with community sites as the blocks. If the assumptions of normality and equality of variances are not satisfied, we will seek appropriate transformations. For the discrete variables, we will use the chi-square test for comparison of distributions in proportions across two or more levels of categorical variables in the two groups in each community¹⁰. The heterogeneity chi-square will be calculated to see if the four sites are homogeneous at baseline. For discrete variables, with natural ordering of categories we will use ridit analysis¹¹ to compare the two groups in each community at baseline. Such analysis will be applicable to any question on the Quality of Life Scale, where answers are on a Likert scale, ranging from "0-not at all", to "4-very much so", or on the Functional Status Scale, ranging from "1-limited a lot", to "3-not limited at all". At baseline, if the two groups do not differ, the mean ridit should be 0.5. The value represents the probability that an individual selected at random from the comparison group reports a more extreme value on the Likert scale than an individual selected at random from the reference group.

2. Intervention evaluation. The primary outcome variables of interest at post-intervention are the various aspects of physical function and quality of life for the patients. We hypothesize that the intervention group will have fewer physical functioning limitations and higher quality of life, than the non-intervention group. For both instruments (Functional Status and Quality of Life), the outcome measures to be compared between the two groups, will include the overall summary value for each instrument as well as the single items which comprise the summary value on each scale. The overall measures are a continuous variable, while the individual items are scored on a Likert scale. To test the null hypothesis of no difference between the two groups on the overall measures, expressed as $H_0: \mu_1 = \mu_2$ we will use two-way ANOVA¹⁰. Subsequently general linear models will be used to evaluate the effect of other variables of interest such as age, income etc., or adjust for their effect as covariates. To test the null hypothesis of no difference between the two groups for the individual items scored on a Likert scale, ridit analysis will be used¹¹.

For items on scales, such as wound healing and sensory awareness, where the response is dichotomous (yes-no), the overall observed rates of complications (yes responses) will be calculated for each group.

^ ^

Denote by (p_{1j}, p_{2j}) the observed rates of complications in the j -th community ($j=1,..,4$) for the intervention group ($I=1$) and the non-intervention group ($I=2$). Then, the overall complication rates in the two groups across the four communities will be estimated

by $\hat{p}_I = \frac{1}{k} \sum_{j=1}^k n_j \hat{p}_{Ij} / \frac{1}{k} \sum_{j=1}^k n_j$ ($j=1,..,4$ and $I=1,2$)

The effect of intervention in the j -th pair is the difference between the two rates $D_j = \hat{p}_{1j} - \hat{p}_{2j}$. The average effect of the intervention across the four communities can be calculated as a simple average $D = \frac{1}{k} \sum_{j=1}^k D_j$, or a weighted average if the communities turn out to be severely imbalanced in sample size.

To test the null hypothesis of no difference between the two types of intervention expressed as $H_0: p_{1j} = p_{2j}$ we will use the Mantel-Haenszel chi-square test¹². Applicability of this test to the analysis of stratified clinical trials is discussed by Fleiss^{11,13}. Similar analysis can be performed for individual functional status items and quality of life items, if we choose to collapse categories of response to two levels. For the dichotomous outcome measures, we will use logistic regression¹⁴, to evaluate the effect and or/adjust for covariates, such as age, income, and other demographic variables. All models will include indicator variables for the communities.

Secondary variables of interest will be anxiety, symptoms, and cost of care. Methods of analysis described above for continuous variables will be used to analyze these outcome measures. Several variables will be measured at both pre- and post-intervention. To assess change over time we will use repeated measures analyses to evaluate statistically significant changes for these variables in the intervention group that are not paralleled in the non-intervention group.

All of the above mentioned analyses can be carried out in SAS¹⁵ statistical package available to the investigators on their office computers.

3. Sample Size Considerations. Power calculations were carried out for the between group comparisons assuming 1) equal sample size $n=100$ in each group for a total of 200 participants equally distributed by community, and 2) $\alpha=0.05$, two sided. For the continuous primary outcome measures, power calculations were carried out for between group comparisons with a two-way ANOVA. With a sample size of 100 in each group, distributed across the communities, we have power of 82% to detect differences of "medium size effects" at $\alpha=0.05$. For example, if the hypothesized means on the Quality of Life Scale (FACT-B) are 110 for the non-intervention group and 100 for the intervention group (See Cella et. al.¹⁶) with a within population standard deviation of 20, we will have power of at least 82% to detect such a difference¹⁷.

For dichotomous variables of interest, using the methodology described by Gail¹⁸ and Donner¹⁹ for sample size calculation in the design of stratified randomized clinical trials, we have power of at least 80% to detect differences in proportions of 65% for the standard care group vs. 40% for the intervention group. The value of approximately 65% 'disability' (defined as completion of activity is very difficult), in one or more upper-body tasks, was reported by Satariano²⁰, in a study of middle-aged and elderly women with breast cancer.

III. Results

Our anticipated n=25 by September 15, 1997 has been exceeded. We currently have 30 women enrolled in the study. This report provides preliminary data on the initial 25 women who have completed the study.

A. Post-Test Interview Data

1. Demographics (please see Table 2)

Table 2 provides demographic data for the two arms of the study separately, and the total sample size. To date, there are 14 control participants and 11 intervention participants. The majority of women are Caucasian (92%), married (72%), and employed prior to surgery (56%). They are well educated, with the majority having at least some college education (68%) and a mean age of 59.8 years. The average household income is in the \$40,000 range. The majority of women had a lumpectomy with axillary node dissection (64%). The mean hospital stay was 27.5 hours. When we exclude women who exceeded the 48 hour stay, the mean hospital stay was 17.9 hours.

2. Improved Surgical Recovery and Self-Care Knowledge

a. *Infection Status* (please see Table 3): The majority of women did not use antibiotics (56%) following their surgery. When prescribed, antibiotics were used either for prevention of infection (40%) or for treatment of infection (4%). Within the **control** group, 29% were prescribed antibiotics by their surgeon to prevent infection, and 7% were prescribed antibiotics to treat infection. Within the **intervention** group, 55% were prescribed antibiotics by their surgeon to prevent infection, and no women were prescribed antibiotics to treat infection.

b. *Surgical Arm Range-of-motion Status* (please see Table 4): Both the intervention and the control groups were pre- and post-tested for arm range-of-motion. Range-of-motion was evaluated on a five point scale where 1 to 4 were defined as limited range-of-motion and 5 was defined as full range-of-motion for the surgical arm. Among **control** participants, 78.8% of women had full range-of-motion before and after surgery and 21.4% of women had full range-of-motion before but became limited after surgery. Among the **intervention** participants, 73% of women had full range-of-motion before and after surgery, 18% of women had full range-of-motion before surgery but became limited after surgery, and 9% of women had limited range of motion before and after surgery.

c. *Breast Self Exam (BSE) Knowledge and Performance*: All participants were evaluated on their knowledge of BSE before and after surgery. Across both groups of women, 92% indicated they knew how to perform BSE. In future reports, we will include results on the specific areas of knowledge related to correct performance of BSE. Currently, we are beginning to observe some differences between the two groups of women on accuracy of performance; however, the data is too limited to report results at this time.

3. Functional Status (ADLs) (please see Table 5)

Functional status data were self-reported by women before and after surgery. The before surgery data were collected by participant recall at the same time post-test data were collected. Participants were questioned about 23 possible limitations in functional status on a three point scale ranging from "not limited at all" to "limited a lot". Both groups reported more limitations after surgery. Common limitations to *both* groups post-surgery were vigorous activity, reaching into a cupboard overhead, and lifting objects over 10 pounds. Please see Table 5 for the most frequently reported limitations by each group. In future reports, we will run statistical comparisons between groups.

4. Symptoms Experienced Following Surgery (please see Table 6)

Participants were asked to report on their symptom experience following surgery. They were first asked if they had experienced any of the 21 listed symptoms during the last two weeks. If they had experienced a symptom, they were then asked to rate the severity on a three point scale (mild, moderate, severe). The **control** group reported a mean of 7.25 symptoms. The mean number of symptoms reported by the **intervention** group was 6.80. The two most commonly reported symptoms by *both* groups were pain and fatigue. When considering symptoms that were reported by 60% or more of either group, the **intervention** group reported three symptoms and the **control** group reported four symptoms. The control group also experienced a wider range of symptoms over-all than the intervention group.

5. Anxiety Level (please see Table 7)

State and trait anxiety were measured for all participants before and after surgery. Both the state and trait instruments consisted of 20 items each, which were rated on a 1 to 4 scale where 1 equals high anxiety and 4 equals low anxiety. Half of the items on each scale are reported in the opposite direction; therefore these items were reversed for analysis. Even with our limited sample size, we were able to see a significant improvement in state anxiety following our **intervention**. The **control** group reported no significant changes after surgery.

6. Quality of Life (please see Table 8)

Quality of life was measured for all participants before and after surgery. Six subscales cover various areas of quality of life: physical well-being, family and social well-being, relationship with doctors, emotional well-being, functional well-being, and additional concerns. Each subscale consists of 2 to 7 items. In this report, all items are based on a 0 to 4 point scale where 0 equals the highest quality of life and 4 equals the lowest quality of life. By using paired t-tests, two significant findings were identified in this preliminary data. *Both* groups reported a significant improvement in emotional well-being when comparing pre- and post-test responses.

7. Use of Health Services (please see Table 9)

All participants were asked about health services they had utilized since surgery. Both groups used a total of seven different types of health services. When looking at *both* groups, 100% of all participants made return visits to their surgeons. However, the

intervention group made a mean number of 2.60 visits to their surgeon, while the **control** group made a mean number 3.07 visits to their surgeon. The **control** group also made more visits for laboratory testing and primary care visits. The most striking difference was with participants who required re-hospitalization after their surgery. Only one woman from the **intervention** group was re-hospitalized, while four women from the **control** group were re-hospitalized in the four weeks following surgery. Our study homecare nurses made an average of 3.18 visits per **intervention** participant, while **control** group participants received an average of 7.78 visits from a community home care agency nurse.

8. Complementary Therapies (please see Table 10)

Of the **intervention** group, 45% used one or more complementary therapy, while 64% of the **control** group used one or more therapies. The most frequently used therapy by *both* groups was "special vitamin therapy". The **intervention** group used 6 different types of therapies and the **control** group used 8 different types of therapies.

9. Out-of-Pocket Expenses

At the time of the post-surgical interviews, many women had not received bills for health services. We will be following up with women to obtain these costs. Therefore, we will report on cost in later reports.

B. Paradox Intervention Protocol Data

Intervention protocol data is being obtained on only the intervention group; therefore this portion of the report is not a comparative analysis with the control group.

1. Demographics Related to the Protocol Intervention (please see Table 11)

The mean number of home visits per participant was 3.18, with a range of two to six visits; the mean number of phone contacts was 3.64; and the mean number of nursing diagnoses identified per participant was 12.36. In terms of nursing time spent, the mean number of minutes of direct nursing care was 53 per visit; the mean amount of time spent per telephone encounter was 7.26 minutes in direct assessment and consultation between patient and nurse; and an additional mean of 2.86 minutes was spent on coordination of care with other health professionals via telephone. Record-keeping per home visit averaged 49.57 minutes.

2. Most Frequently Occurring Nursing Diagnosis (Problems) (please see Table 12)

For the overall group of participants (n=11), thus far 20 nursing diagnoses (problems) have been utilized, with a mean of 12.39 diagnoses per-participant. Twelve of these diagnoses are included in our standard protocol. The remaining 8 diagnoses have been opened to meet the individual needs of the various participants.

3. Most Frequently Used Nursing Interventions (please see Table 13)

To date, 104 different interventions have been carried out by the intervention nurses to meet the needs of the women in the intervention arm of the study. Thirty-six

interventions are part of the standard protocol for all intervention subjects. The additional interventions (68) were implemented to individualize care for the various women's specific needs.

IV. Discussion *(Results in relation to specific aims and hypothesis)*

The following discussion is based on our preliminary data (n=25). Future reports will provide much clearer trends in the data.

A. Specific Aims and Hypothesis

When compared to conventional short-stay surgical care, the subacute care in-home intervention is targeted to help women attain optimal recovery during their immediate post-surgical phase and assist them in regaining their pre-surgical health status prior to initiating adjuvant therapy. This study is testing the hypothesis that when compared to women with breast cancer who receive conventional post-surgical care, recipients of the subacute care intervention will report:

1. **Improved Surgical Recovery and Self-Care Knowledge**
2. **Higher Functional Status (ADLs)**
3. **Fewer Symptoms**
4. **Lower Anxiety Levels**
5. **Higher Quality of Life**
6. **Less Frequent Use of Health Services**
7. **Fewer Out-of-Pocket Payments for Health Care Services**

B. Post-Test Interview Data Discussion

1. Demographics

The **intervention** group was slightly older than the **control** group. Based on this difference, it might be presumed that the **intervention** group would have a more difficult recovery; however these women showed comparable or better improvements in physical functioning and emotional well-being. We realize, with our limited sample, that no definitive conclusions about group differences can be reported at this time.

2. Improved Surgical Recovery and Self-Care Knowledge

- a. **Infection Status:** The groups are very comparable at this time regarding antibiotic use. The only trend to note is that the **intervention** group did not received any antibiotics for treatment of infection. In the **control** group, one participant received antibiotics to treat an infection.
- b. **Surgical Arm Range-of-Motion:** In terms of range-of-motion, *both* groups were comparable. However, the **control** group had one more participant than the **intervention** group who became limited in range-of-motion following surgery. Since our protocol specifically targets teaching range-of-motion, this is a trend we would expect to continue as data collection proceeds.
- c. **Breast Self Exam (BSE) Knowledge and Performance:** In future reports, we will target the correct procedure for performing BSE since the vast majority of women believe they do know how to do BSE. Our intervention nurses are finding a

variety of gaps in knowledge related to correct procedures and timing for BSE. We expect some interesting differences in groups once we have a larger sample.

3. Functional Status (ADLs)

At this time, the two groups are reporting some limitations in common and some differences. *Both* groups are reporting increased limitation related to endurance (vigorous activities), lifting, and reaching activities. We will watch for these trends to become more established or change as we accrue further participants. Also, in the future, we will report on the severity of the predominant limitations.

4. Symptoms Experienced Following Surgery

During analysis we identified specific items that some women were not responding to such as breast tenderness (due to surgery on both breasts), level of sexual interest, and weight loss. In calculating means, these subjects were omitted. In future interviews, we will monitor these items closely, and may consider omitting questions that significant numbers of women do not answer.

Overall, the **control** group reported more symptoms and a wider range of symptoms than the **intervention** group. Our intervention protocol emphasizes a preventive approach to post-surgical symptoms, therefore, we anticipate that this trend will continue as our number of participants increases.

5. Anxiety Level

Our preliminary results show a significant decrease in state anxiety for the **intervention** group after surgery which represents one of the specific aims of our study. Our intervention focuses on anxiety reduction techniques and emotional support for women following breast cancer surgery. We hope to see this trend continue.

6. Quality of Life

The only significant changes over time for *both* groups were related to improved emotional well-being. There were three additional areas within the **intervention** group where improved quality of life was noted on the post-test, however, this improvement did not reach a level of significance. In the **control** group, there were two areas that did not reach statistical significance but showed a slight improvement in quality of life. We would expect to see additional improvements in the various areas of quality of life for the **intervention** group as our sample size increases.

7. Use of Health Services

A major goal of this study is to provide cost effective, comprehensive, physical/emotional care and health education to women following breast cancer surgery. These initial trends demonstrate that the women in the **intervention** group are requiring fewer health services and visits overall than the **control** group. In addition, the women in the **intervention** arm of the study appear to be recovering comparably or better than women in the **control** arm of the study. We hope to see a continuation of these very preliminary trends in our data.

8. Complementary Therapies

It appears that a significant number of breast cancer patients are using complementary therapies in addition to customary medical care. We realize that complementary therapies are becoming a national trend among cancer patients. We believe that complementary therapies may make a significant contribution to out-of-pocket costs. In our next report, we will include out-of-pocket costs participants have spent on complementary therapies in addition to other healthcare costs.

9. Out-of-Pocket Expenses

These costs will be included in the next report since we are still gathering this data on our initial participants.

C. Paradox Intervention Protocol Data Discussion

1. Demographic Protocol Discussion (please see Tables 9 and 11)

When comparing our intervention data with our post-test data, we are able to begin to see some differences between our **control** and **intervention** participants. The **intervention** participants are requiring less than half the number of home visits when compared to **control** participants who receive agency home care. This may be partially accounted for by the fact that our intervention nurses provide self-care instruction during their visits, rather than performing care for the woman. This approach encourages independence and self-care competency for women in the intervention arm of the study. In addition, the intervention nurses make an average of 3.64 telephone contacts to the women, which assists the women in managing their own care. If we are able to demonstrate that the **intervention** women do as well or better than the **control** women with a statistically significant sample, our data will contribute to the identification of the optimal amount of nursing care needed in the first two weeks following breast cancer surgery. While we do not have information on agency home care in terms of the amount of time spent in the home per visit, record keeping, and coordination of care by the nurses, we feel that the less than one hour per home visit spent by our intervention nurses along with the 50 minutes of record-keeping time is very reasonable and cost effective.

2. Nursing Diagnoses (problems) Discussion (please see Table 12)

Our standardized protocol provides for assessment of 7 major categories which are specific for the post-surgical breast cancer patient: constipation, pain, fatigue, anxiety, quality of life, incision care, and educational needs. In addition to the protocol assessment, our home care nurses individualize their assessment to each woman's needs. Some of these additional areas of need deal with problems such as nausea, community resource needs, depression, and seroma teaching needs. While we note that a variety of women have these types of additional needs, there is currently not a strong enough trend to add further diagnoses to our protocol. The additional nursing diagnoses, at this time, appear to be addressing unique needs of individual women, and we will continue to assess these extra needs on an per participant basis.

3. Protocol Intervention Discussion (please see Table 13)

Our **control** participants are reporting over twice the number of home visit from standard agency home than we are providing to the **intervention** participants. We suspect that one of the differences is that standard agency home nursing care focuses primarily on reimbursable skills done for or to the woman, such as incision and drain care.

We have found that the **intervention** women benefit from a comprehensive home nursing care visit focusing on self-care education to care for their incision and drain. Further, our protocol incorporates services that are currently not reimbursable but seem essential to the woman's rehabilitation, such as emotional support, quality of life counseling, and health education about prevention of post-surgical complications and restorative care.

D. Adjustments in Accomplishing Tasks of the Study

1. Adjustments have been made to the participant age criteria. The change was from 45 years and older to 21 years and older, to accommodate the rising numbers of young women diagnosed with breast cancer. We had originally chosen age 45 due to the statistical increase after this age nationwide; however our participating surgeons encouraged us to include all adult women, due to the age trends found in their practices.

2. Geographic areas have been specifically delimited. Surgeons in the various communities care for patients within a 200 mile or greater radius of their practices. Thus, we have limited recruitment to a 40 mile radius (based on the woman's home address) from the surgeon's office in order to provide nursing care in the home, including protocol visits and urgent needs, and to control mileage expenses.

3. The control group will have two branches. Originally, it was assumed that if a patient was not randomized into the intervention arm of the study, she would not receive any type of home care. In some cases, women not randomized into the intervention, are receiving home care ordered by their surgeon. Our statistician will account for these branches of the control group, i.e., controls without home care, and controls with surgeon-initiated home care. Intervention participants will be compared to both control groups separately as well as the total pooled control participants.

4. Our study criteria calls for a 48 hour or less hospital stay. In five cases (2 interventions and 3 controls), women who were recruited into the study stayed longer than 48 hours. One woman developed an elevated temperature which kept her in the hospital for 96 hours. Another participant had a hospital stay of 81 hours due to the unexpected extent of her surgery. The three other participants exceeded the 48 hours by no more than 6.5 hours. While all surgeons who participate in the study understand our 48 hour criteria, we expect that a few hospital stays will exceed our time limit throughout the study. We do not want to eliminate these participants at the time their hospitalization exceeds 48 hours, as this will confound our randomization procedures.

These participants will continue their participation in the study, but their data will be controlled during analysis. Our statistician will run the analysis with and without these types of cases to determine if they significantly affect the results.

5. We plan to expand the chart audit to include post-protocol complications for both the control and intervention participants. We are interested in evaluating if the intervention participants have differing numbers or types of complications which develop after the post-surgical subacute phase of care.

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

CONCLUSIONS

I. Summary of Results

From the data obtained thus far, it appears that women in the intervention arm of the study, who are having short-stay surgery for breast cancer, are receiving follow-up care in the home on an average of 3.2 visits and 3.6 phone calls in the first 14 days post-operatively by a registered nurse. Our control women, who receive agency home care, are currently receiving over twice the number of home visits as our intervention group. Generally, with our limited sample, we are finding that the control visits are excessive and could foster dependency upon the nurse. Our goal is to empower women through self-care instruction and support. We anticipate that many self-care questions can be handled through phone contact with a registered nurse and approximately two to five visits will meet the needs that arise following the wide variety of surgical procedures performed for breast cancer. This finding could potentially translate into national policy for discharge planning in terms of cost, length of hospital stay, and optimal amount of nursing care needed.

II. National Trends

Currently, managed care companies in several states advocate hospital stays of 24 hours or less for breast cancer surgery, arguing that savings of up to 75% of total cost can be realized. Detractors refer to such short-stays as the "drive through mastectomy" and say that it lowers costs to the detriment of the patient, who is sent home with drainage equipment to monitor, dressings to change, and other care needs formerly performed by hospital nurses. The controversy prompted New York Lt. Governor, Betsy McCaughey Ross, to push Congress to pass a 48-hour minimum stay law, similar to the one that already covers birthing²¹. In an effort to generate support for the legislation, the Sapien Health Network has posted an online petition that will be presented to Congress during Breast Cancer Awareness Month, October 1997. Similarly, the Breast Cancer Patient Protection Act, sponsored by Representative Rosa L. DeLauro (D-Conn.) would require insurance companies to pay for at least 48 hours of hospital stay for women undergoing mastectomies and 24 hours for women undergoing lymph node removal²². In California's Senate, a bill introduced by Assembly woman Liz Figueroa (D-Freemont), is being considered, which would allow the attending physician and surgeon to determine the length of stay after consultation with the patient. Furthermore, it requires a follow-up visit by a licensed health care provider within 48 hours of discharge when ordered by a physician or surgeon²³.

III. Future Work

Recommendations for future work includes follow-up on surgical complications which occur two or more weeks after surgery (i.e. seroma formation, lymphedema, limited arm mobility, infection, emotional issues, quality of life/body image issues). While our study does not address these later

post-surgical complications, we are noticing during chart audits that women from both the control and intervention groups are experiencing some of these complications. It would be interesting to track group differences.

Secondly, a comparison of our protocol with the actual components of standard agency home nursing care following surgery could provide valuable information about optimal nursing care in the home. For instance, it would be interesting to know how much time the agency nurse spends with control participants, how much time is spent documenting visits, and how much time is spent coordinating care with other health professionals. Further, it would be interesting to note which nursing diagnoses were routinely addressed, and what nursing interventions were documented per visit. Ultimately, differences in post-surgical outcomes would be of the greatest importance. A chart audit of the various home care agencies would provide much of this information, along with a follow up of patient charts in the surgeon's offices to monitor outcomes.

Another area worthy of investigation is tracking of medications used during surgery and the related post-surgical symptoms, such as pain and nausea. Such a study could assess specific intra-surgery medications (i.e. antiemetics and steroids) which are linked to more favorable post-surgical outcomes for short-stay patients.

A fourth area for future work could focus on the involvement of a spouse or partner in a woman's treatment, rehabilitation, and health maintenance after breast cancer. Specifically, the degree of involvement in health activities by the spouse or partner could be assessed. An intervention study could then target fostering partner involvement such as reminding the woman to: 1) perform monthly BSE, 2) schedule routine mammograms and 3) keep follow-up appointments. The partner could also be informed of the types of personal and household help a woman may need during chemotherapy or radiation treatment. Further, partners could be instructed on palpation of breast tissue to help women assess any variations felt during BSE. These types of supportive activities may help women more quickly regain their family roles and promote their longevity. The spouse or partner has a significant investment in these types of outcomes, and may be highly motivated to participate with adequate professional support and education. Such educational sessions with spouses/partners could help decrease health visits and services, thereby controlling costs in the long run.

A fifth area for future work may involve identifying the time period in which women are most receptive to teaching related to their health and wellness. Many of our affiliated hospitals have attempted pre-operative classes to teach post-surgical care. For the most part these classes have been discontinued. Pre-operatively, women are struggling with the new diagnosis of cancer, and deciding upon their surgical options. Our intervention nurses are finding that women are highly motivated to learn self-care activities immediately after their surgery and in their own homes. In addition, our control women continue to have questions at 3-5 weeks after surgery when they are interviewed. We suspect there may be an optimal time for teaching/learning that would be best for women and most cost effective for health professionals to provide education.

Finally, the women in this study could be followed into survivorship. In previous research done by the Principal Investigator, it is clear that there are still health risks in the survivor population. Finding could be compared with previous work, and specific interventions studies could be designed to meet the needs of survivors to maintain their physical and emotional wellbeing.

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

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Table 1

Data Collection Schedule

| MEASURES | ENTRY-PRE SURGERY | 4 WEEKS POST-SURGERY |
|--|----------------------|-------------------------|
| Demographic Data Sheet | X | |
| Functional Status (Modified SF-36) | X | X |
| Symptom Experience (Modified) | | X |
| Healing Process | | X |
| Anxiety (Spielberger State-Trait) | X | X |
| Quality of Life FACT-B | X | X |
| Out-of-Pocket Health Costs | | X |
| Chart Audit (Stage of Disease, Type of Surgery, Lymph Node Involvement) | | X |

Table 2

Demographics

| | Intervention | | Control | | Total | |
|--|--------------|-------|---------|-------|-------|-------|
| | n | % | n | % | n | % |
| Ethnicity | | | | | | |
| Caucasian | 10 | 90.9% | 13 | 92.9% | 23 | 92.0% |
| Other | 1 | 9.1% | 1 | 7.1% | 2 | 8.0% |
| Marital Status | | | | | | |
| Married | 8 | 72.7% | 10 | 71.4% | 18 | 72.0% |
| Divorced/Separated | 1 | 9.1% | 2 | 14.3% | 3 | 12.0% |
| Never married | 1 | 9.1% | 1 | 7.1% | 2 | 8.0% |
| Widowed | 1 | 9.1% | 1 | 7.1% | 2 | 8.0% |
| Employment Status | | | | | | |
| Employed before surgery | 3 | 27.3% | 11 | 78.6% | 14 | 56.0% |
| Not employed before surgery | 8 | 72.7% | 3 | 21.4% | 11 | 44.0% |
| Education | | | | | | |
| Completed graduate/profess. degree (Post bac. degree) | 3 | 27.3% | 4 | 28.6% | 7 | 28.0% |
| Completed some college | 2 | 18.2% | 5 | 35.7% | 7 | 28.0% |
| Completed some high school | 3 | 27.3% | 1 | 7.1% | 4 | 16.0% |
| Completed college | 1 | 9.1% | 2 | 14.3% | 3 | 12.0% |
| Completed high school | 1 | 9.1% | 2 | 14.3% | 3 | 12.0% |
| Completed grade school | 1 | 9.1% | 0 | 0.0% | 1 | 4.0% |
| No formal education | 0 | 0.0% | 0 | 0.0% | 0 | 0.0% |
| Type of Surgery | | | | | | |
| Lumpectomy w/ node removal | 8 | 72.7% | 8 | 57.1% | 16 | 64.0% |
| Mastectomy w/ node removal | 2 | 18.2% | 4 | 28.6% | 6 | 24.0% |
| Mast. without node removal | 1 | 9.1% | 2 | 14.3% | 3 | 12.0% |

| | Intervention | | | | Control | | | | Total | | | |
|------------------------------------|--------------|------|------|-------------|---------|------|------|-------------|-------|------|------|-------------|
| | n | M | SD | Min/ Max | n | M | SD | Min/ Max | n | M | SD | Min/ Max |
| Income* | 6 | 40 | 24 | 18-70 | 12 | 51 | 21 | 20-76 | 25 | 47 | 28 | 18-76 |
| Age | 11 | 61.7 | 14.7 | 37-84 | 14 | 56.7 | 11.9 | 33-82 | 25 | 58.9 | 13.1 | 33-84 |
| Hospital stay | 11 | 30.8 | 29.8 | 6-96 | 14 | 24.8 | 17.4 | 4-55 | 25 | 27.5 | 23.3 | 4-96 |
| Hospital stay ≤48 hours | 9 | 18.0 | 9.0 | 6-30 | 11 | 17.8 | 11.5 | 4-33 | 20 | 17.9 | 10.2 | 4-33 |

*M, SD, Min/Max rounded to the nearest thousand

Table 3

Surgical Recovery and Self Care Knowledge

Number Who Used Antibiotics to Prevent vs Treat Infection

| | Used Antibiotics | | | | Did not use Antibiotics | | Total | |
|--------------|----------------------|-------|--------------------|------|-------------------------|-------|-------|--------|
| | To prevent infection | | To treat infection | | | | | |
| | n | % | n | % | n | % | n | % |
| Intervention | 6 | 54.5% | 0 | 0.0% | 5 | 45.5% | 11 | 100.0% |
| Control | 4 | 28.6% | 1 | 7.1% | 9 | 64.3% | 14 | 100.0% |
| Total | 10 | 40.0% | 1 | 4.0% | 14 | 56.0% | 25 | 100.0% |

Table 4

Surgical Recovery and Self-Care Knowledge**Change in Surgical Arm Range of Motion (ROM)
from Before to After Surgery**

| | | <i>AFTER</i> | |
|------------------------------|----------------------|---------------------|------------------------|
| | | Full ROM | Limited ROM |
| Intervention (n = 11) | <i>BEFORE</i> | n = 8 73% | n = 2 18% |
| | | n = 0 0% | n = 1 9% |
| | | <i>AFTER</i> | |
| | | Full ROM | Limited ROM |
| Control (n = 14) | <i>BEFORE</i> | n = 11 78.8% | n = 3 21.4% |
| | | n = 0 0% | n = 0 0% |

Table 5

Four Most Frequently Reported Limitations In Functional Status Over Time

| | Intervention | | | | |
|--|---------------------|----------|--------------|----------|---------------|
| | <i>Before</i> | | <i>After</i> | | <i>Change</i> |
| | n | % | n | % | % |
| Reaching into cupboard overhead | 1/11 | 9% | 9/10 | 90% | 81% |
| Vigorous activity | 4/11 | 36% | 9/11 | 82% | 46% |
| Lifting and carrying groceries | 0/11 | 0% | 9/11 | 82% | 82% |
| Lifting objects over 10 pounds | 3/10 | 30% | 8/10 | 80% | 50% |

| | Control | | | | |
|--|----------------|----------|--------------|----------|---------------|
| | <i>Before</i> | | <i>After</i> | | <i>Change</i> |
| | n | % | n | % | % |
| Vigorous activity | 2/13 | 15% | 12/13 | 92% | 77% |
| Moderate activity | 2/14 | 14% | 11/14 | 79% | 65% |
| Reaching into cupboard overhead | 1/14 | 7% | 10/14 | 71% | 64% |
| Lifting objects over 10 pounds | 0/13 | 0% | 8/13 | 62% | 62% |

Table 6
Symptoms Experienced Following Surgery

| | Mean | Reported range of symptoms | Possible range of symptoms |
|--------------|------|-------------------------------|-------------------------------|
| Intervention | 6.80 | 1 - 10 | 0 - 21 |
| Control | 7.25 | 2 - 12 | 0 - 21 |

| | Intervention n | Control n | %* |
|----------|-------------------|--------------|-------|
| Pain | 4 | 5 | 35.7% |
| mild | 3 | 4 | 28.6% |
| moderate | 1 | 0 | 0.0% |
| severe | 1 | 0 | 0.0% |
| total | 8/11 | 9/14 | 64.3% |

Symptoms Reported by 60% or More of Either Group

| | Intervention n | Control n | %* |
|------------------------------------|-------------------|--------------|-------|
| Pain | | | |
| mild | 4 | 5 | 35.7% |
| moderate | 3 | 4 | 28.6% |
| severe | 1 | 0 | 0.0% |
| total | 8/11 | 9/14 | 64.3% |
| Fatigue | | | |
| mild | 2 | 5 | 35.7% |
| moderate | 6 | 8 | 57.1% |
| severe | 1 | 0 | 0.0% |
| total | 9/11 | 13/14 | 92.8% |
| Numbness | | | |
| mild | 4 | 5 | 35.7% |
| moderate | 3 | 3 | 21.4% |
| severe | 1 | 1 | 7.1% |
| total | 8/11 | 9/14 | 64.2% |
| Limitations of arm movement | | | |
| mild | 4 | 5 | 35.7% |
| moderate | 3 | 3 | 21.4% |
| severe | 1 | 1 | 7.1% |
| total | 8/11 | 9/14 | 64.2% |
| Weakness | | | |
| mild | 4 | 6 | 42.9% |
| moderate | 3 | 3 | 21.4% |
| severe | 1 | 0 | 0.0% |
| total | 8/11 | 9/14 | 64.3% |

*Percentages do not add up to 100% since report is based on only the participants who experienced the symptoms.

Table 7

STATE Anxiety Over Time

1 = most anxious to 4 = least anxious

| Group | Intervention (n = 11) | | Control (n = 14) | |
|-----------------|--------------------------|-----|---------------------|-----|
| Time | M | SD | M | SD |
| Before surgery: | 2.58* | .89 | 2.91 | .84 |
| After surgery: | 3.15* | .87 | 3.06 | .82 |

TRAIT Anxiety Over Time

1 = most anxious to 4 = least anxious

| Group | Intervention (n = 11) | | Control (n = 14) | |
|-----------------|--------------------------|-----|---------------------|-----|
| Time | M | SD | M | SD |
| Before surgery: | 3.00 | .52 | 3.37 | .37 |
| After surgery: | 3.22 | .59 | 3.41 | .43 |

*Significant $p \leq .008$

Table 8

Quality of Life Subscale

0 = highest quality of life to 4 = lowest quality of life

| Subscales | Intervention Group (n = 11) | | | | | | Control Group (n = 14) | | | | | |
|-----------------------------|-----------------------------|------|-----------|---------------|------|-----------|------------------------|------|----------|---------------|------|-----------|
| | Before Surgery | | | After Surgery | | | Before Surgery | | | After Surgery | | |
| | M | SD | Min/Max | M | SD | Min/Max | M | SD | Min/Max | M | SD | Min/Max |
| Physical wellbeing | 0.50 | 0.55 | 0-1.67 | 0.71 | .55 | 0.17-2.17 | 0.56 | 0.51 | 0-1.83 | 0.58 | 0.55 | 0-2 |
| Social and family wellbeing | 0.69 | 0.87 | 0-2.67 | 0.46 | 0.34 | 0-1 | 0.35 | 0.46 | 0-1.25 | 0.48 | 0.54 | 0-1.5 |
| Relationship with doctors | 0.55 | 1.21 | 0-4 | 0.41 | 0.63 | 0-2 | 0.43 | 0.62 | 0-2 | 0.36 | 0.66 | 0-2 |
| Emotional wellbeing | 1.59* | 0.99 | 0.17-3.0 | 1.03* | 1.07 | 0.17-3.5 | 1.26** | 0.97 | 0-3.17 | 0.92** | 0.71 | 0-2.33 |
| Functional wellbeing | 1.27 | 1.30 | 0-4 | 1.01 | 0.82 | 0-2.57 | 1.07 | 0.70 | 0-2.14 | 1.17 | 0.65 | 0.29-2.57 |
| Additional concerns | 1.29 | 0.69 | 0.29-2.43 | 1.55 | 0.50 | 0.86-2.57 | 1.29 | .78 | .29-2.71 | 1.21 | 0.74 | 0.29-2.57 |

* Significance $p \leq .05$ ** Significance $p \leq .07$

Table 9

Health Services/Visits

| Services/Visits | Intervention (n = 11) | | | Control (n = 14) | | |
|--|--------------------------|------|---|---------------------|------|---|
| | n | % | Mean number of visits by those who used service | n | % | Mean number of visits by those who used service |
| Surgeon | 11 | 100% | 2.60 | 14 | 100% | 3.07 |
| Laboratory | 4 | 36% | 1.50 | 6 | 43% | 1.67 |
| Primary Care | 0 | 0% | 0.00 | 2 | 14% | 1.00 |
| Emergency Room | 1 | 9% | 1.00 | 1 | 7% | 1.00 |
| Hospital | 1 | 9% | 1.00 | 4 | 29% | 1.00 |
| Social Worker | 0 | 0% | 0.00 | 0 | 0% | 0.00 |
| Home Care Nurse <i>from study</i> | 11 | 100% | 3.18 | 0 | 0% | 0.00 |
| Home Care Nurse <i>from other providers</i> | 1 | 9% | 2.00 | 9 | 64% | 7.78 |
| Housekeeping | 1 | 9% | 2.00 | 1 | 7% | 2.00 |
| Transportation | 0 | 0% | 0.00 | 0 | 0% | 0.00 |

Table 10

Complementary Therapies Used

| Intervention (n = 11) | | | Control (n = 14) | |
|----------------------------------|----------|-----------|-------------------------|-----------|
| Used at least one therapy | | | 5/11 = 45% | |
| | | | 9/14 = 64% | |
| Specific Therapies | n | %* | n | %* |
| Special Vitamin Therapy | 3 | 27% | 6 | 43% |
| Therapeutic Massage | 1 | 9% | 2 | 14% |
| Guided Imagery | 1 | 9% | 2 | 14% |
| Acupuncture | 1 | 9% | — | — |
| Special Cancer Diet | 1 | 9% | — | — |
| Special Cultural Therapies | 1 | 9% | — | — |
| Spiritual Healing | — | — | 2 | 14% |
| Homeopathic Remedies | — | — | 2 | 14% |
| Chiropractic Treatment | — | — | 1 | 7% |
| Relaxation Audio Tapes | — | — | 1 | 7% |
| Relaxation Video Tapes | — | — | 1 | 7% |

*Percentages do not add up to 100% since not all participants used complementary therapies, and some used more than one therapy.

Table 11

Demographic Protocol Data

| Variable | M | SD | Range |
|--|----------|-----------|--------------|
| Number of visits per participant | 3.18 | 1.08 | 2 - 6 |
| Number of phone contacts per participant | 3.64 | 1.43 | 2 - 6 |
| Number of nursing diagnosis problems opened per participant | 12.36 | NA | NA |
| Home visit direct care time per visit (minutes) | 53.29 | 15.86 | 30 - 90 |
| Home visit record-keeping time per part. (minutes) | 50.14 | 25.39 | 20 - 120 |
| Home visit coordination of care time per participant (minutes) | 4.71 | 8.25 | 0 - 30 |
| Telephone direct care time per contact (minutes) | 7.26 | 5.08 | 0 - 15 |
| Telephone coordination of care time with other health providers per telephone contact (minutes) | 2.86 | 5.31 | 0 - 15 |

Table 12

Frequency of Nursing Diagnoses (Problems) Used

| Nursing Diagnosis (Problems) | | |
|---|---|-----------------------------|
| Categories | Protocol Diagnosis | Number of Times Used |
| I. Constipation | 1. Constipation | 11 |
| II. Pain | 2. Pain, acute | 11 |
| III. Fatigue | 3. Activity intolerance | 11 |
| IV. Anxiety | 4. Anxiety | 11 |
| V. Quality of life | 5. Alteration in quality of life | 14 |
| VI. Incision care | 6. Knowledge deficit, milk drain | 11 |
| | 7. Knowledge deficit, empty drain | 11 |
| | 8. Knowledge deficit, recording drainage | 11 |
| | 9. Skin integrity/surgery | 11 |
| VII. Health education | 10. Knowledge deficit, lymphedema | 11 |
| | 11. Knowledge deficit, BSE | 11 |
| | 12. Knowledge deficit, ROM affected arm | 11 |
| Categories | Additional Diagnosis | Number of Times Used |
| VIII. Depression | 13. Depression | 3 |
| IX. Quality of life | 14. Knowledge deficit - community resources | 2 |
| X. Incision care | 15. Knowledge deficit - dressing change | 4 |
| | 16. Knowledge deficit - seroma | 2 |
| | 17. Knowledge deficit - signs and symptoms | 2 |
| | 18. Self-care deficit - dressing change | 5 |
| | 19. Self-care deficit - clogged drainage tube | 2 |
| XI. Nausea | 20. Nausea | 3 |

Table 13

Frequency of Interventions Used

| Protocol Interventions | | Methods | Frequency |
|-------------------------------|---------------------------------------|----------------|------------------|
| 1. | Give educational materials | Teaching | 26 |
| 2. | Medications | Teaching | 16 |
| 3. | Breast self exam | Teaching | 15 |
| 4. | Breast self exam | Evaluating | 14 |
| 5. | Quality of life | Assessing | 14 |
| 6. | Quality of life | Evaluating | 13 |
| 7. | Active listening | Counseling | 12 |
| 8. | Exercise - range of motion | Teaching | 12 |
| 9. | Lymphedema prevention | Teaching | 12 |
| 10. | Patient, empty drain | Teaching | 12 |
| 11. | Anxiety | Assessing | 11 |
| 12. | Anxiety management | Evaluating | 11 |
| 13. | Drainage tube, milking | Assessing | 11 |
| 14. | Exercise - range of motion | Evaluating | 11 |
| 15. | Fatigue | Assessing | 11 |
| 16. | Lymphedema knowledge | Evaluating | 11 |
| 17. | Over-the-counter medications | Prescribing | 11 |
| 18. | Constipation - bowel movement | Assessing | 11 |
| 19. | Drainage, recording | Evaluating | 11 |
| 20. | Pain control | Assessing | 11 |
| 21. | Patient, milking drainage tube | Teaching | 11 |
| 22. | Patient, recording drainage | Teaching | 11 |
| 23. | Support re' individual | Counseling | 11 |
| 24. | Drain, emptying | Evaluating | 11 |
| 25. | Fatigue | Evaluating | 11 |
| 26. | Infection control | Teaching | 11 |
| 27. | Pain control | Evaluating | 11 |
| 28. | Skin integrity - wound | Assessing | 11 |
| 29. | Sleep/rest hygiene | Teaching | 11 |
| 30. | Functional level (surgical arm) | Evaluating | 11 |
| 31. | Drainage tube, milking | Evaluating | 11 |
| 32. | Skin care - wound | Teaching | 11 |

| Protocol Interventions, continued | | Methods | Frequency |
|-----------------------------------|--|---------------|-----------|
| 33. | Support group | Referring | 11 |
| 34. | Anxiety management | Teaching | 11 |
| 35. | Constipation - bowel management | Evaluating | 11 |
| 36. | Skin care - wound | Evaluating | 11 |
| Additional Interventions | | Methods | Frequency |
| 37. | Drain, empty | Assessing | 9 |
| 38. | Dressing change (ability) | Assessing | 9 |
| 39. | Hope instillation | Counseling | 9 |
| 40. | Patient, dressing change | Teaching | 9 |
| 41. | Dressing change | Evaluating | 8 |
| 42. | Dressing change | Nursing skill | 8 |
| 43. | Incision/wound care | Evaluating | 7 |
| 44. | Range of motion, arm | Demonstrating | 7 |
| 45. | Drainage, recording | Assessing | 6 |
| 46. | Caregiver, dressing change | Teaching | 5 |
| 47. | Coping skills | Teaching | 5 |
| 48. | Disease process - cancer | Teaching | 5 |
| 49. | Family communication, enhancement among | Counseling | 5 |
| 50. | Seroma formation, Signs and symptoms .. | Teaching | 5 |
| 51. | Exercise - range of motion | Assessing | 4 |
| 52. | Medications, alter | Prescribing | 4 |
| 53. | Nausea | Assessing | 4 |
| 54. | Resources, how to obtain | Teaching | 4 |
| 55. | Support group | Counseling | 4 |
| 56. | Treatment surgery | Teaching | 4 |
| 57. | Breast self exam | Demonstrating | 3 |
| 58. | Caregiver, drain emptying | Teaching | 3 |
| 59. | Caregiver, milk drainage tube | Teaching | 3 |
| 60. | Caregiver, recording drainage | Teaching | 3 |
| 61. | Coping enhancement | Counseling | 3 |
| 62. | Drainage tube, nurse unclogs | Nursing skill | 3 |
| 63. | Exercise therapy, general | Teaching | 3 |
| 64. | Fatigue, management of | Teaching | 3 |

| Additional Interventions, continued | | Methods | Frequency |
|-------------------------------------|---|---------------|-----------|
| 65. | Lifestyle changes | Counseling | 3 |
| 66. | Quality of life, physical | Counseling | 3 |
| 67. | Resource needs | Assessing | 3 |
| 68. | Symptom control/treatment toleration . . . | Teaching | 3 |
| 69. | Constipation - bowel management | Teaching | 2 |
| 70. | Depression | Assessing | 2 |
| 71. | Depression | Evaluating | 2 |
| 72. | Distraction techniques | Teaching | 2 |
| 73. | Drain, empty | Monitoring | 2 |
| 74. | Drainage tube, unclogging | Demonstrating | 2 |
| 75. | Energy management | Prescribing | 2 |
| 76. | Health care provider regarding early complications | Consulting | 2 |
| 77. | Health system utilization - appropriate . . . | Teaching | 2 |
| 78. | Medications, over-the-counter | Teaching | 2 |
| 79. | Nausea | Evaluating | 2 |
| 80. | Nutrition | Teaching | 2 |
| 81. | Pain management, non-prescriptive drugs | Prescribing | 2 |
| 82. | Pain management, prescriptive drugs . . | Prescribing | 2 |
| 83. | Role performance, altered | Counseling | 2 |
| 84. | Seroma formation, Signs and symptoms . | Assessing | 2 |
| 85. | Situational | Counseling | 2 |
| 86. | Anxiety | Counseling | 1 |
| 87. | Body image | Counseling | 1 |
| 88. | Cold therapy | Prescribing | 1 |
| 89. | Constipation/impaction management . . | Prescribing | 1 |
| 90. | Depression | Counseling | 1 |
| 91. | Depression | Evaluating | 1 |
| 92. | Exercise - range of motion | Prescribing | 1 |
| 93. | Family practice/internist | Referring | 1 |
| 94. | Functional level | Assessing | 1 |
| 95. | Guided imagery | Teaching | 1 |

| Additional Interventions, continued | | Methods | Frequency |
|-------------------------------------|---|------------|-----------|
| 96. | Infection status | Evaluating | 1 |
| 97. | Infection, Signs and symptoms | Assessing | 1 |
| 98. | Insomnia | Evaluating | 1 |
| 99. | Medication effectiveness | Assessing | 1 |
| 100. | Prevention of complications | Teaching | 1 |
| 101. | Problem solving/decision making | Counseling | 1 |
| 102. | Quality of life, partner | Counseling | 1 |
| 103. | Quality of life, social/family | Counseling | 1 |
| 104. | Symptom control, self monitoring of | Teaching | 1 |

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

CURRICULUM VITAE
Appendix A

Principal Investigator

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1969 B.A. Michigan State University, East Lansing, Michigan
1973 M.A. Michigan State University, East Lansing, Michigan
1975 R.N. Henry Ford Hospital School of Nursing, Detroit, Michigan
1980 M.S.N. Wayne State University, Detroit, Michigan
1988 Ph.D. Michigan State University, East Lansing, Michigan

Registered Nurse, licensed in the State of Michigan; Number 111964
Certified Clinical Specialist in Medical-Surgical Nursing, American Nurse Credentialing Center,
Current through December 31, 1997.

PROFESSIONAL WORK EXPERIENCE

| <i>Title</i> | <i>Location</i> | <i>Date</i> |
|---------------------------------------|---|-----------------|
| Associate Professor | College of Nursing | 7/95 to present |
| Assistant Professor | Michigan State University East Lansing, Michigan | 9/80 to 7/95 |
| Practitioner, Hypertension Program | Dr. Clifford Hale Lansing, Michigan | 10/80 to 1/83 |
| Instructor, Medical/Surgical | Lansing Community College Lansing, Michigan | 3/80 to 8/80 |
| Director, Camp Health Clinic | Camp Tamarack Ortonville, Michigan | 6/79 to 9/79 |

| | | |
|------------------------------|---|--------------|
| Instructor, Cardiac Care | School of Nursing Hurley Medical Center Flint, Michigan | 9/77 to 6/78 |
| Instructor, Medical/Surgical | Lansing Community College | 9/75 to 6/77 |
| Staff Nurse/Charge Nurse | E. W. Sparrow Hospital Lansing, Michigan | 9/75 to 5/77 |

| |
|---------------------------------|
| INTERNATIONAL EXPERIENCE |
|---------------------------------|

| | | |
|-------------------------------------|---|----------------------------|
| Oncology Lecturer and Consultant | Christian Medical College College of Nursing Vellore, South India | 1/91 to 4/91 Sabbatical |
| Oncology Consultant | Ministry of Health Division of Nursing Trinidad, West Indies | 6/89 to 7/89 |
| Oncology Lecturer | Langmore Health Foundation Trinidad, West Indies | 3/90 to 4/90 |

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Given, C.W., & Given, B.A. (Co-principal Investigators) (5/92-4/97) Rural Partnership Linkage for Cancer Care. (Wyatt, G. Nurse Presenter). National Institutes of Health/National Cancer Institute, grant #RO1CA56338-03. (\$2,076,266). Funded.

Petropoulos, E. (Principal Investigator) Minority International Research Training Application to NIH. (Wyatt, G. Oncology Nurse Collaborator for India). Folgarty International Center, National Institutes of Health. (\$1,138,678). Funded 9/1/94.

Given, B.A. (Principal Investigator) (1993-1996) Family Home Care For Cancer A Community Based Model. (Wyatt, G. Nurse Collaborator). National Institute for Nursing Research. (\$2,002,617). Funded.

Wyatt, G. (Principal Investigator) (1993-1994) A Comparative Assessment of Short Term Sequelae of Elderly Women Who Experience Surgery Only vs Surgery Plus Adjuvant Therapy for Treatment of Breast Cancer. American Cancer Society Institutional Grants to Michigan State University. (\$12,153). Funded.

Wyatt, G. (Principal Investigator) (1992-1994) Quality of Life Assessment of Long Term Female Cancer Survivors. Oncology Nursing Society. (\$7,500). Funded.

Wyatt, G. (Principal Investigator) (1992) Breast Cancer Survivors: An Exploration of Quality of Life Issues. College of Nursing, Research Initiation Grant, Michigan State University. (\$2,000). Funded.

Metzler, J. (Principal Investigator) (1989-91) Internationalizing Curricula for Rural Michigan Community Colleges. (Wyatt, G. conducted 4 day workshop for nursing faculty statewide on internationalizing the curriculum). Kellogg Foundation University Outreach Grant. Funded.

Dimitrov, N. (Principal Investigator) (1985) Cancer Education Grant. (Wyatt, G., Nursing Curriculum Consultant). U. S. Department of Health and Human Services, National Institutes of Health. Funded.

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| AWARD |
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Bristol-Myers Oncology Division Research Award, Oncology Nursing Foundation (Awarded 1992).

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| ORGANIZATION PARTICIPATION |
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- International:*** Phi Beta Delta - Honor Society for International Scholars
Michigan International Nursing Education Resource
- National:*** Oncology Nursing Society
American Nurses' Association
Nurse Healers Professional Association
Sigma Theta Tau International
- Regional:*** Capitol Area District Nurses Association
Midwest Nursing Research Society
- State:*** Michigan Nurses' Association
- Local:*** Alpha Psi Chapter of Sigma Theta Tau (Officer 1990-94)
Alpha Alpha Chapter of Phi Beta Delta
- College of Nursing:*** Search Committee--Tenure Stream, Chair 1995 - 1997
Ad Hoc Retirement Committee, Chair 1995-1996
Research Center Committee 1996-1997
Ad Hoc Two Year Scheduling Committee 1995 - 1997
Ad Hoc Faculty Development Committee 1994
Ad Hoc Course Coordinators Committee 1993-1997
Ad Hoc Self Study Committee 1993-1994
Ad Hoc Space Committee 1993-1994
Faculty Advisory Council 1988-1990
- University Committees:*** University Hearing Board 1993-97
University Curriculum Committee 1995-96
Review Committee for the Institute of International Health 1995
International Studies and Programs Consulting and Advising
1989-1994
Institute of International Health Committee, 1989-1992
Academic Council 1989-1990
Faculty Council 1989-1990

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| PRESENTATIONS |
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Wyatt, G. Preliminary Testing of a Long-Term Quality of Life Instrument. Poster presentation for Oncology Nursing Society Congress (May 3, 1997) New Orleans, LA.

Wyatt, G. Physical and Psychosocial Needs of Midlife and Older Women Following Surgery and Adjuvant Therapy for Breast Cancer. Paper presentation for Fourth National Conference on Cancer Nursing Research (January 1997) Panama City, FL.

Wyatt, G. New DOD Funding for Breast Cancer Transition Care Research, Presentation for the College of Nursing, Research Center Seminar Series, Michigan State University (November 1996) East Lansing, MI.

Wyatt, G. Quality of Life of Women Experiencing Cancer. Poster presentation for Supportive Care Conference (June 1996) Toronto, Canada.

Wyatt, G. Models for Assessing Quality of Life Among Female Cancer Survivors. Presentation for Family Practice Research Day XIX (May 1996) Michigan State University, East Lansing, MI.

Wyatt, G. Therapeutic Touch with Critically Ill Patients. Presentation for Annual Conference of the Association of Critical Care Nurses (May, 1996) Novi, MI.

Wyatt, G. Therapeutic Touch with Various Patient Populations. Presentation for Latino Midwest Medical Student Association, (March 1996) University of Michigan, Ann Arbor, MI.

Wyatt, G., Schiffman, R., & Tiedje, L.B. Abstract and Poster Preparation Workshop. Presentation for Sigma Theta Tau Alpha Psi Chapter, (December 1, 1995) East Lansing, MI.

Wyatt, G.K. Physical, Psychosocial, and Financial Effects of Surgery in Midlife and Older Women Experiencing Breast Cancer. Paper presentation for Sigma Theta Tau International Biannual, (November 3-8, 1995) Detroit, Michigan.

Wyatt, G.K. Quality of Life of Female Cancer Survivors. Poster presentation for Kellogg Community/University Health Partnerships. (September 26-29, 1995) East Lansing, MI.

Wyatt, G. & Dimmer, S. 25 Continuing Education Contact Hours. Therapeutic Touch. Presentation for Michigan Nurses Association. (August 11-13, 1995) Kellogg Biological Station, Hickory Corners, MI.

Wyatt, G. K. Physical, Psychosocial, and Financial Effects of Surgery in Midlife and Older Women Experiencing Breast Cancer. Paper presentation for Family Practice Research Day XVIII. (May 18, 1995) East Lansing, MI.

Wyatt, G.K. Short-Term Sequelae of Midlife and Older Breast Cancer Patients. Paper presentation for Twentieth Annual Oncology Nursing Society Congress. (April 26-29, 1995) Anaheim, California.

Wyatt, G.K. Short-Term Sequelae of Midlife and Older Breast Cancer Patients. Paper presentation for Midwest Nursing Research Society 19th Annual Conference. (April 1-4, 1995) Kansas City, Missouri.

Wyatt, G.K. Physical, Psychosocial, and Financial Effects of Surgery in Midlife and Older Women Experiencing Breast Cancer. Poster presentation for Community Liaison Research Day, Michigan Capital Medical Center (March 30, 1995) Lansing, Michigan.

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| INVITED SPEAKER |
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Wyatt, G. (1997, January) Breast Cancer: Post-Surgical Care. Invited speaker for Great Lakes Nursing Cancer Conference to be held October 21, 1997, Novi, MI.

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| MEDIA COVERAGE |
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Wyatt, G. (article). (Fall 1996) INVESTIGATOR FOCUS, article featuring research by G. Wyatt. Cancer Center at Michigan State University News, East Lansing, MI.

Wyatt, G. (press interview). (February 18, 1997) Longer Hospital Stays Not Always the Answer. News release through Michigan State University Division of University Relations.

Wyatt, G. (press interview). (March 10, 1997) Michigan State University Study to Help Women Diagnosed with Breast Cancer. News release through Michigan State University Division of University Relations.

Wyatt, G. (press interview). (March 25, 1997) Mammograms Urged at Age 40. News release through Michigan State University Division of University Relations.

Wyatt, G. & Bloomfield, M. (television interview). (April 11, 1997) WELG Channel 22 Cable Television. (Aired twice a day April 14 through April 20, 1997).

Breast Cancer Source Guide, Michigan State University Media Communications. (June 2, 1997).

Wyatt, G. (radio interview). (July 17, 1997) Nursing Care Following Short-Stay Breast Cancer Surgery. With D. Krolick, Broadcast/ Photo Division of University Relations, Michigan State University, for National 24 Hour Radio Information Hotline.

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| LAY PRESENTATIONS |
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Wyatt, G. The Breast Cancer Experience. Presentation for Unitarian Universalist Church Women's Group (November 19, 1996) East Lansing, MI.

Wyatt, G. Therapeutic Touch: Conceptual Change of Health Care Providers. Poster presentation for College of Nursing, Homecoming Poster Session, Michigan State University (October 11, 1996) East Lansing, MI.

Wyatt, G. Sigma Theta Tau Alpha Psi Chapter Anniversary. Poster presentation for College of Nursing Homecoming Celebration (October 1996) East Lansing, MI.

Wyatt, G. Volunteer for Camp Catch A Rainbow for Kids with Cancer (July 18-28, 1996) Muskegon, MI.

updated 8/28/97

BARBARA A. GIVEN
Curriculum Vitae

NAME: Barbara Given

HOME ADDRESS: 1655 Boulevard Drive
Okemos, Michigan 48864

HOME TELEPHONE: (517) 349-1945
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BUSINESS ADDRESS: Institute for Managed Care
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Michigan State University
East Lansing, MI 48824-1317

BUSINESS TELEPHONE: (517) 432-4326
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PRESENT POSITION: Professor

PRESENT RESPONSIBILITIES: Teach — graduate level courses in primary care, role, research, and thesis guidance; Associate Director for Cancer Control, Cancer Center; and Director for Research, Institute for Managed Care at Michigan State University

BASIC PREPARATION (Diploma): 1960, Miami Valley Hospital

BACCALAUREATE DEGREE: 1964, Ohio State University
Major: Nursing

MASTER'S DEGREE: 1965, Ohio State University
Major (Clinical): Medical-Surgical Nursing
Major (Functional): Administration

DOCTORAL DEGREE: 1976, Michigan State University
Administration and Higher Education

ADDITIONAL EDUCATIONAL EXPERIENCES: Fellow in Medical Education, OMERAD, Office of Medical Education and Research, Michigan State University, 1972-73.

PROFESSIONAL WORK EXPERIENCE:

| | | |
|--|--|---------------------------|
| Director of Research | Institute for Managed Care College of Human Medicine | 1996 to Present |
| Adjunct Faculty | Department of Family Practice College of Human Medicine | 1991 to Present |
| Director Center for Nursing Research | College of Nursing Michigan State University | 1990 to December, 1996 |
| Associate Director Cancer Prevention and Control | Cancer Center Michigan State University | 1989 to Present |
| Professor | College of Nursing Michigan State University | 1980 to Present |
| Professor and Director of Graduate Program | College of Nursing Michigan State University | 1980 to 1988 |
| Associate Professor and Assistant Director for the Graduate Program; Instructor of Undergraduate Medical-Surgical Nursing and Research Methods | School of Nursing Michigan State University | 1966 to 1980 |
| Staff Nurse | Grant General Hospital Columbus, Ohio | 1963 to 1964 |
| Assistant Clinical Instructor | Miami Valley Hospital Dayton, Ohio | 1960 to 1961 |

PROFESSIONAL ACTIVITIES:

Michigan State University College of Nursing

Student Affairs Committee, 1970-74

Bylaws Committee, 1972-74

Graduate Task Force (Develop Master's in Nursing), Chairperson, 1974-76

Ad Hoc Faculty Interview Guidelines, Chairperson, 1975

Ad Hoc for Nursing in Campus Ambulatory Care Center, Chairperson, 1974-76

Graduate Program Advisory Committee, Chairperson, 1976-78

Research & Development Committee, 1981-86, Ad Hoc 1987-88

Faculty Affairs/Faculty Development, 1978-79

Faculty Affairs Committee, 1979-81

Faculty Practice Committee, 1984-90

Graduate Curriculum Committee, 1988-91

Curriculum Committee, 1996-1997

Doctoral Program Ad Hoc Chairperson, 1990-1995, Ad Hoc Committee, 1995-present

Awards Committee, 1991-1996

Home Care Task Force, 1992

CHARLES W. GIVEN
Curriculum Vitae

NAME: Charles William Given

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Okemos, Michigan 48864

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BUSINESS ADDRESS: Department of Family Practice
B-100 Clinical Center
Michigan State University
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BUSINESS FAX: (517) 355-7700

EMAIL ADDRESS: givenc@pilot.msu.edu

PRESENT RESPONSIBILITIES: Professor and Associate Chairperson for Research, Department of Family Practice

EDUCATION: Bachelor of Science, Economics and Sociology, Ohio State University, Columbus, Ohio, 1963
Master of Science, Sociology, Ohio State University, Columbus, Ohio, 1965
Doctor of Philosophy, Sociology, Michigan State University, East Lansing, Michigan, 1969

HONORS AND AWARDS:
College of Human Medicine Distinguished Faculty Award, 1996
Arthur Victor Distinguished Faculty Award in Health Care Delivery, 1996
Joint American Academy of Family Physicians Foundation/American Academy of Family Physicians Grant Awards Council, Recognition of Service as Peer Reviewer, 1996
Michigan State University Distinguished Faculty Award, 1997
Nominated for Michigan Association Governing Boards Award, 1997

MAJOR RESEARCH INTERESTS:
Long-term care of the elderly through the family and home care, patterns of care, institutional, and other congregate arrangements. The impact of interventions on the courses and outcomes of chronic diseases especially cancer. The uses of data systems for practice management and improved early detection and continuing home care of patients across the life span.

PROFESSIONAL WORK EXPERIENCE:
1969-70 Director, Planning and Program Development, Regional Medical Programs and Assistant Professor of Sociology, Michigan State University
1970-71 Director, Planning Program Development, Regional Medical Programs and Assistant Director, Urban Survey Research Unit, Michigan State University

PROFESSIONAL WORK EXPERIENCE (continued):

1971-78 Assistant Professor, Department of Community Health Science, Michigan State University
1979-83 Associate Professor, Department of Community Health, Michigan State University
1983-85 Associate Professor, Department of Family Practice, Michigan State University
1985-present Professor, Department of Family Practice, Michigan State University
1993-present Associate Chairperson for Research, Department of Family Practice, Michigan State University.
1994-present Program Leader, Primary Care Programs, Cancer Center at Michigan State University

PROFESSIONAL ACTIVITIES:

Departmental

Curriculum Committee. Planning and implementing courses in college curriculum related to: Epidemiology and Biostatistics; Aging and Long Term Care; Clinical Rotations in Geriatric Assessment; Quality Assurance and Cost Containment; Evaluation of Health Services and Programs

By-Laws Committee

Reappointment Promotion and Tenure Committee

Recruitment Committee; Executive Committee

College

College Advisory Committee

Graduate Studies and Research Committee

Research Committee

Planning Committee — Family Practice Research Days

Admissions Committee

Ad Hoc Grievance Committees

Life Long Cancer Care Center Task Force

Rural Breast Cancer Screening Task Force

Rural Research in Health Task Force

Human Health Programs Executive Committee on Aging

Comprehensive Cancer Center — Psychosocial Research Program Group

Electronic Medical Records Committee

Research and Graduate Committee — College of Human Medicine

Cancer Center at Michigan State University, American Cancer Society Institutional Grant -- Reviewer for Junior Faculty Research Grants

University

Research Initiation Grant Review Committee

Graduate Council

Rural Research Health Care Working Group, W.K. Kellogg Partnership Grant

BSRG Grant Review

University Committee on Intellectual Integrity

Regional

Reviewer, Southwest Michigan Area Health Education Corporation Research Day

Participation, facilitation, Grand Rapids Area Medical Education Corporation Research Network

Research Facilitation, Community-Based Family Practice Residency Programs (Midland, Saginaw, Grand Rapids, Lansing)

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

DoD GRANT ABSTRACTS Appendix B

Wyatt, G. (1997). Extended abstract. Submitted to Department of Defense Breast Cancer Research Program for conference to be held October 31 - September 4, 1997 in Washington, D.C.

Wyatt, G. (1997). Lay/Public abstract. Submitted to Department of Defense Breast Cancer Research Program for conference to be held October 31 - September 4, 1997 in Washington, D.C.

A SUBACUTE CARE INTERVENTION FOR SHORTSTAY BREAST CANCER SURGERY

Gwen Wyatt, RN, PhD

Michigan State University College of Nursing

With professional nursing care, do women recovering from breast cancer surgery fare better at home than in the hospital? To test this theory, researchers at Michigan State University's Colleges of Nursing and Human Medicine are undertaking a project that will determine how much and what kind of care women need.

Women who have had a mastectomy or lumpectomy face many physical and emotional adjustments. Until recent years, these women received up to 10 days of post-surgical hospital care. Today, women are discharged as soon as six hours after surgery, and must rely upon themselves or family to manage one or more surgical drains and monitor other aspects of their recovery at home. Breast surgeries done on this outpatient basis give nursing staff very little time to teach women what they need to know in order to avoid post-surgical complications.

Over the next four years, this study will offer comprehensive follow-up care to women coping with breast cancer. The care will be provided in the form of home visits and telephone contacts by a registered nurse during the first two weeks after surgery.

To participate in the study, a woman must be 21 years of age or older, be scheduled for breast cancer surgery and, ultimately, discharged from the hospital within 48 hours. Funding for the project is provided by the United States Army Medical Research and Materiel Command, Department of Defense. The project director is Dr. Gwen Wyatt, professor of nursing. This nursing study is designed to support women in their homes after breast cancer surgery and improve their recovery.

The six month start-up phase of the study has been completed and women are now being recruited into the study. Nine surgeons in two Michigan communities are currently participating by encouraging their breast cancer patients to take part in the study. It is anticipated that up to fifty women will be entered into the study during the first year. During year two, the study will add additional recruitment sites. To date, there has been no attrition from the study. While data is still too limited for analysis, both physicians and participants report anecdotally that they are pleased with the outcomes of the study.

A SUBACUTE CARE INTERVENTION FOR SHORT-STAY BREAST CANCER SURGERY

Gwen Wyatt, RN, PhD

Michigan State University College of Nursing

With in-home nursing care, women discharged after short-stay breast cancer surgery may recover as well in their home as they have traditionally recovered in the hospital setting. The purpose of this study is to add to the scientific basis for providing subacute care in the home, by testing the effects of an immediate post-operative intervention designed to facilitate quality of life as well as physical and psychological well-being after diagnosis and surgery for breast cancer.

A 2-group randomized clinical trial with repeated measures will examine the effects of the intervention. The control group (n=100) will receive customary medical care. The intervention group (n=100) will receive individual physical and psychological support in the home through 2 telephone calls and 2 in-home visits from a registered nurse within the first 14 post-operative days. To participate in the study, a woman must be at least 21 years of age, be scheduled for breast cancer surgery and, ultimately, discharged from the hospital within 48 hours.

Data collection for both groups will occur at recruitment prior to surgery and again at 4 weeks post-surgery before beginning adjuvant therapy. Between group comparisons of quality of life, physical and psychological well-being will be made. We hypothesize that, compared to the control group, recipients of the intervention will report 1) higher quality of life, 2) fewer wound complications, 3) higher physical functioning, 4) lower anxiety levels, 5) fewer symptoms, and 6) lower out-of-pocket expenses associated with health care during the intervention period.

KEYWORDS: **Breast Cancer, Short-Stay Surgery, Subacute Nursing Care,
Post-Surgical Outcomes, Costs.**

This work was supported by the U.S. Army Medical Research and Materiel Command under DAMD17-96-1-6325

The six month start-up phase of the study has been completed and women are now being recruited into the study. Nine surgeons in two Michigan communities are currently participating by encouraging their breast cancer patients to take part in the study. It is anticipated that up to fifty women will be entered into the study during the first year. During year two, the study will add additional recruitment sites. To date, there has been no attrition from the study. While data is still too limited for analysis, both physicians and participants report anecdotally that they are pleased with the outcomes of the study.

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

PUBLISHED JOURNAL ARTICLES **Appendix C**

Wyatt, G., Kurtz, M.E., Friedman, L.L., Given, B., Given, C.W. (1996). Preliminary testing of the long-term quality of life (LTQL) instrument for female cancer survivors. Journal of Nursing Measurement, 4(2), 153-170.

Wyatt, G.K.H. & Friedman, L.L. (1996). Development and testing of a quality of life model for long-term female cancer survivors. Quality of Life Research, 5, 387-394.

Wyatt, G. & Friedman, L.L. (1996). Long-term female cancer survivors: Quality of life issues and clinical implications. Cancer Nursing, 19(1), 1-7.

Kurtz, M.E., Wyatt, G., Kurtz, J.C. (1995). Psychological and sexual well-being, philosophical/spiritual views, and health habits of long-term cancer survivors. Health Care for Women International, 16, 253-262.

Wyatt, G., Kurtz, M.E., & Liken, M. (1993). Breast cancer survivors: An exploration of quality of life issues. Cancer Nursing, 16(6), 440-448.

Preliminary Testing of the Long-Term Quality of Life (LTQL) Instrument for Female Cancer Survivors

Gwen Wyatt, R.N., Ph.D.
Margot E. Kurtz, Ph.D.
Laurie L. Friedman, Ph.D.
Barbara Given, R.N., Ph.D., F.A.A.N.
Charles W. Given, Ph.D.

The purpose of this study was to develop a quality of life instrument for long-term female cancer survivors. A factor analysis ($n = 188$) of 34 items resulted in the Long-Term Quality of Life (LTQL) instrument. Internal consistency was high for the four subscales: somatic concerns ($\alpha = .86$), spiritual/philosophical views of life ($\alpha = .87$), fitness ($\alpha = .92$), and social support ($\alpha = .88$). These four factors are congruent with Ferrell's four theoretical domains of quality of life developed for women with breast cancer. Content validity was supported through interrater agreement of subscale items. Significant correlations between the LTQL and the CaRES, an established measure of quality of life, support the concurrent validity of the LTQL. Construct validity was supported by differential subscale scores according to demographic and health status data. Although the LTQL retained all of Ferrell's four domains of quality of life (physical, psychological, social, and spiritual) within one instrument, individual items reconfigured to suggest an overlapping of domains for the long-term female cancer survivor. This research suggests that the LTQL warrants further testing and may be a useful measure of quality of life in long-term female cancer survivors.

It is estimated that 575,000 women will be diagnosed with cancer in 1996. The relative 5-year survival rate for all cancers is 54% (American Cancer Society, 1996). Because over half of all women who experience cancer survive five years or longer, one of the critical issues for health professionals is the quality of life of these long-term survivors. It has been shown that length of survivorship is not necessarily associated with the presence of fewer or lesser concerns about the

From Michigan State University (G. Wyatt, M. E. Kurtz, B. Given, C. W. Given) and the Research Institute on Addictions, Buffalo, NY (L. L. Friedman).

cancer experience (Polinsky, 1994). A holistic quality of life instrument would be useful to examine the way women's lives change as a consequence of long-term survival of their cancer.

Quality of life is often conceptualized as a multidimensional construct, but there is no consensus in the literature on the specific dimensions of quality of life (Padilla, Grant, & Ferrell, 1992). Quality of life is broadly defined by a wide range of physical and psychological characteristics and limitations that describe an individual's ability to function and derive satisfaction from life (Walker, 1987). Health-related quality of life "generally applies to the level of well-being and satisfaction associated with an individual's life and how this is affected by disease, accidents, and treatments" (Grant, Padilla, Ferrell, & Rhiner, 1990, p. 260). Current practice shows a tendency to qualify the term by speaking of health-related quality of life when referring to individuals responding to the effects of disease and treatment (Padilla, Mishel, & Grant, 1992). In this article, the terms "quality of life" and "health-related quality of life" are used interchangeably, referring to a multidimensional interaction of life domains (bio-psycho-social-spiritual), particularly the importance of physical concerns, social support needs, health behaviors and beliefs, and spiritual/philosophical issues (Wyatt & Friedman, 1996a).

Much of the research on quality of life in female cancer survivors has focused on the first year following diagnosis, when women experience intensive treatment, e.g., surgery, radiation, and/or chemotherapy (Ciampi, Lockwood, Sutherland, Llewellyn-Thomas, & Till, 1988; Coates *et al.*, 1987; McCaughan & Sexton, 1991; Padilla *et al.*, 1990; Schag, Ganz, & Heinrich, 1991). A small body of research has followed women for up to 5 years from diagnosis, although there is no universally accepted definition of the "long-term survivor." In this study, "long-term" survivorship was considered surviving 5 years or more from the point of cancer diagnosis.

Aaronson (1990) reviewed quality of life instruments and identified the need to develop multidimensional quality of life instruments that are brief, psychometrically robust, and guided by appropriate theoretical models of the relationship among quality of life domains. State-of-the-art measures that reflect complex changes in oncology care are now beginning to be developed. However, Ferrell (in Ferrans, 1990) notes that quality of life is a difficult area of research due to the "sea of beginning studies" rather than established theories and evidence (p. 21). The purpose of the current study was to enhance the new generation of instruments by developing a measure that specifically assesses quality of life of the long-term survivor in multiple domains of life, including the often omitted domain of spirituality.

Quality of Life of Long-Term Cancer Survivors: Limitations in Current Measures

Grant and colleagues (1990) reviewed multidimensional quality of life instruments for their psychometric properties, content domains, and practical aspects. With regard to content, instruments were assessed as focusing on physical well-being,

psychological well-being, and/or interpersonal well-being. Although all but one of the measures included more than one content area, none included spiritual well-being. In addition, many of these instruments were developed for use with short-term survivors or currently ill patients and have not been tested with longer-term survivors. Another review of quality of life scales for cancer patients (Donovan, Sanson-Fisher, & Redmond, 1989) identified only two instruments that addressed the spiritual domain:

The Cancer Rehabilitation Evaluation System (CaRES) and its Short Form (CaRES-SF) are two of the more recently developed and widely used measures of short-term quality of life in cancer patients (Schag et al., 1991). The CaRES and CaRES-SF measure five concepts of quality of life: physical, psychosocial, medical interaction, marital, and sexual issues. These instruments have been used to assess quality of life in female lung cancer patients (Sarna, 1993) and to predict psychosocial risk in newly diagnosed patients with breast cancer (Ganz et al., 1993; Schag et al., 1993).

Ganz, Schag, Lee, and Sim (1992) found that 13 months after surgery for breast cancer scores on the CaRES dropped to lower levels, indicating either that quality of life had improved, or that the CaRES was less sensitive to quality of life issues in this sample of longer-term survivors. In particular, the CaRES lacks a spiritual dimension. Finally, although the CaRES has proven to be an effective instrument with short-term survivors, all items are worded to reflect problems, which may not resonate with long-term survivors who are feeling optimistic about their future.

Grant and associates (1992) proposed a conceptual model of quality of life that added spirituality to the traditional bio-psycho-social model of quality of life (see Padilla et al., 1990). They developed a quality of life instrument for bone marrow transplant patients (QOL-BMT) assessing all four domains of life. Even more recently, Cohen and colleagues (Cohen, Mount, Tomas, & Mount, 1996) assessed the importance of spiritual well-being among all cancer patients.

Other investigators have included the spiritual domain in combination with another domain (Ferrans & Powers, 1985), or as a single focus (Highfield, 1992). Ferrans and Powers (1985; also Ferrans, 1990) developed an instrument tapping four different life domains, reflected in four subscales (health and functioning, socioeconomic, family, and psychological/spiritual). Their psychological/spiritual scale included specific aspects of religious and psychological life satisfaction, such as happiness, peace of mind, faith in God, and control over life.

Conceptual Basis of the Long-Term Quality of Life (LTQL) Instrument

Ferrell (1993) suggested the application of a broad physical-psycho-social-spiritual framework to breast cancer survivors. The holistic Ferrell model, upon which the current instrument was based, consists of four domains of quality of life: Physical well-being, encompassing areas such as symptom management; psychological well-being, covering concerns such as fear of recurrence, anxiety, and depression; the social concerns domain, including altered family and friendship roles and

relationships; and finally, spiritual well-being, addressing the meaning of illness, religious beliefs, and heightened awareness of mortality as a result of cancer.

Ferrell and colleagues (Ferrell, Dow, & Grant, 1995; Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995) recently expanded the 1993 model by revising their quality of life instrument to be tested with cancer survivors. The length of survivorship among their sample ranged from 4 months to 28 years, with a mean survival of 5.7 years. Testing of the revised version of their instrument (the QOL-CS) supported the importance of including the spiritual domain along with the physical, social, and psychological domains.

In developing a quality of life instrument, the current study chose to follow the course set by Grant and associates (1992), Ferrell (1993), and Dow *et al.* (1996), who included existential as well as religious beliefs and attitudes in the spiritual domain, while attempting to keep the life domains broad. Using the broad domains from the Ferrell (1993) framework, instrument development and subsequent item generation began with focus group discussions in which the goal was to be completely open to the survivors' areas of interest and concern. Thus, the current study built upon previous work on quality of life measures, while enhancing those measures by allowing long-term female survivors to shape and define the dimensions most relevant to their lives. Further, the current study sought to refine and strengthen the spirituality/existential domain, which, to date, has received less attention than other quality of life dimensions. Finally, unlike the Ferrell and associates (1995a, 1995b) studies, the present study focused on long-term survivors of 5 years and longer.

Development of Items and Content Validation

The process of developing the LTQL instrument was "qualitative to quantitative," in which analysis of focus groups was used to assess the expressed concerns and issues of long-term female survivors. Four focus group discussions were conducted with 11 long-term female cancer survivors. Focus group participants ranged in age from 40 to 79 years (mean = 61), and all had survived breast cancer for 5 to 14 years, with a mean survival of 10 years. Two focus group participants had also survived a second type of cancer for at least 5 years. Broad, open-ended questions were asked, based on Ferrell's (1993) four domains of quality of life (see Wyatt, Kurtz, & Liken, 1993, for a more complete review of the focus group process and outcomes).

Based on focus group discussions, a minimum of five items for each of 13 content areas were written, with each statement reflecting an attribute of the content area. Approximately half of the items were worded positively to reflect increased quality of life, and half negatively to reflect decreased quality of life. More items than would be retained in the final instrument were intentionally generated so that when items were deleted during statistical analyses, enough would remain to form viable subscales.

Content validity was assessed by submitting all items to an independent senior research team, consisting of three researchers—one psychometrician and two

researchers experienced in oncology nursing and instrument development. The three judges were asked to determine whether the items fit appropriately into the categories for which they were written, whether any other items should be included in each category, and whether the range of possible items was covered. The team of judges gave feedback on wording, readability, and the appropriateness and comprehensiveness of statements for each content domain. This editing and feedback process was done twice.

In addition, one focus group participant, who was also a nurse, was asked to provide feedback about wording and content of the items. She examined the questionnaire for redundancy, clarity, comprehensiveness, and accuracy of content derived from the focus group discussions. Minor revisions in wording, but no substantive changes, were suggested by the judges and the focus group member. All items were retained at this point. The items were then scrambled and the content categories deleted. Finally, one of the expert judges reviewed the scrambled items to ensure a sufficiently mixed, but not distracting, order of items.

Description, Administration and Scoring of the LTQL

After this initial evaluation, the 67 remaining items were organized into a 5-point scale format, to assess the extent to which the item applied to the respondent: 0 (*not at all*), 1 (*a little*), 2 (*a fair amount*), 3 (*much*), and 4 (*very much*). Additional items were added on a separate page to gather demographic data. The LTQL was designed to be administered by mail, as part of a packet containing other written measures. It was intended that participants would complete the LTQL in their homes.

On some items, a high score (i.e., 4) would be indicative of high quality of life, whereas on others, a score of 4 would indicate low quality of life. When the LTQL was developed, it was intended that items would form subscales, and that item scores would be recoded when necessary to ensure that subscale scores would be comparable to scores on the CaRES, with higher scores indicating *lower* quality of life.

The LTQL consisted of 67 original items, assessing 13 content areas, including eating habits, body image, apparel, pain, exercise, change in senses, change in social support, desire to be of service of others, relationships with health-care providers, susceptibility to cancer, change in perception of health and illness, spiritual guidance for health decisions, and change in philosophical view of life. These 13 content areas reflect Ferrell's four domains, but specific categories differ somewhat within each domain (see Wyatt & Friedman, 1996b, for discussion of domain comparison).

Psychometric Assessment of the LTQL

In order to assess the psychometric properties of the LTQL, the following research questions were addressed:

1. What is the reliability and validity of the Long-Term Quality of Life (LTQL) instrument?

2. What are the major issues regarding quality of life as reported by long-term female cancer survivors when measured by the LTQL instrument?
3. How does quality of life, as measured by the LTQL, differ among women of differential demographic and health status?

METHOD

Participants

The tumor registry of a Michigan hospital recruited three-hundred and fifty female cancer survivors who had been diagnosed in 1987 or earlier. Mailing labels were handled by the registry staff to protect survivors' confidentiality. Ten percent ($n = 35$) of the questionnaires sent out were not completed because the women had died. Another 20% ($n = 70$) of the women could not be contacted because forwarding addresses were not available. Of the remaining women, 78% ($n = 191$) returned the questionnaires, and 188 had useable data. The majority of the respondents were Caucasian (83%), married (64%), and not employed (73%). Fifteen percent had not graduated from high school, 27% were high school graduates, 37% had attended some college, and 22% had completed college or beyond. Ages ranged from 22 to 92, with a mean age of 60.56 years. All of the women were survivors of cancer—over half (58%) of breast cancer, 13% of uterine cancer, with the remainder representing other cancers affecting women. Length of survivorship ranged from 5 to 33 years, with a mean survivorship of 8.42 years.¹

Additional Instruments

The CaRES (Schag & Heinrich, 1990) was used to aid in the validation of the LTQL. The CaRES measures five domains of quality of life—physical, psychosocial, medical interaction, marital, and sexual—and has been used successfully to assess quality of life in short-term cancer survivors. The CaRES was selected as a comparison measure for its record of reliability and validity and recent use with cancer patients. For an earlier version of the CaRES, internal consistency of all the subscales was high (mean $\alpha = .81$). In addition, test-retest reliability, and concurrent, discriminant, and convergent validity were supported in a sample of cancer patients (Schag, Heinrich, Aadland, & Ganz, 1990). Although it does not assess the spiritual domain, the CaRES includes physical and psychosocial items

¹Although data on the women who did not return their questionnaires are not available, a comparison of the current sample with the total tumor registry population of living women who were diagnosed with cancer from 1985 (when the registry became computerized) to 1988 was done. Results indicate that the subsample of women who participated in this study were likely comparable to the general tumor registry of women with cancer. Among those in the computer-accessible tumor registry, the majority of the women were Caucasian (95%) and married (56%). Ages ranged from less than 29 to 99 years, with a modal age range of 60-69 and a median age of 60. Of those women with specifically female cancers, 74% had breast cancer, and 26% had uterine or cervical cancer. Information about length of survivorship of the entire registry population is unavailable.

TABLE 1. Demographics (*n* = 188)

| | <i>n</i> | % |
|-------------------|----------|----|
| Ethnicity | | |
| Caucasian | 173 | 83 |
| Other | 15 | 7 |
| Marital status | | |
| Married | 119 | 64 |
| Widowed | 32 | 17 |
| Divorced | 20 | 11 |
| Other | 17 | 8 |
| Employment status | | |
| Work outside home | 68 | 36 |
| Unemployed | 117 | 73 |
| Missing data | 3 | 1 |
| Education | | |
| Grade school | 10 | 5 |
| Some high school | 18 | 10 |
| High school grad | 51 | 27 |
| Some college | 69 | 37 |
| College grad | 22 | 12 |
| Grad/professional | 18 | 10 |
| Cancer site | | |
| Breast | 108 | 58 |
| Uterine | 24 | 13 |
| Cervical | 15 | 8 |
| Ovarian | 7 | 4 |
| Head & neck | 7 | 4 |
| Lymphoma | 5 | 3 |
| Lung | 2 | 1 |
| Missing Data | 20 | 9 |

| Variable | <i>n</i> | Mean | SD | Range |
|-----------------------|----------|-------------|-------------|----------------|
| Age | 188 | 60.56 | 13-72 | 22-92 |
| Income | 175 | \$32,714.00 | \$20,269.00 | \$5,000-75,000 |
| Survivorship in years | 180 | 8.42 | 5.31 | 5-33 |

that initially seemed similar to many of the concepts presented in the focus groups. In addition, both the CaRES and the LTQL instruments use a 0 to 4 scale with identical anchors.

Procedure

Mailing packets were prepared for participants, including the newly developed LTQL instrument, the CaRES, demographic questions, and an explanatory letter. Packets were ordered with the introductory letter on top, the consent form, then the demographic section, the LTQL next, and the CaRES last. The rationale behind this order was that, because the CaRES was professionally formatted and published, it was expected to be the most "respondent friendly" of the instruments when item fatigue might otherwise set in. Also, the CaRES included more potentially sensitive items, such as those dealing with death, dying, and sexuality. It was expected that

by completing the LTQL before the CaRES, participants would have a chance to become comfortable responding to the questionnaires before tackling the more sensitive items. Women who chose to participate in this study completed the questionnaires and consent form, and returned them to the investigators in the self-addressed stamped envelope.

Preparation for Data Analysis. Once data collection was complete, responses to the 67 items were entered into an SPSS analysis package. Scores of 32 items were reversed so that all items could be scored in the same direction, such that a *high* score indicated *low* quality of life, as with the CaRES. Because there were missing data, a conservative regression substitution was performed to predict the missing responses on both the LTQL and on the CaRES. To ensure accurate estimation on missing data, 30% ($r^2 = .30$) was used as the minimum criterion for the regression substitution. There were more missing data on the CaRES than on the LTQL items. The lower response rate on the CaRES might be a result of respondent fatigue, as the CaRES was presented last in the packet.

RESULTS

Factor Analysis

A factor analysis was conducted to compare statistically generated factors to the original dimensions developed from the focus groups. To counteract sampling error in factor analysis, Nunnally (1978) recommends having 10 times as many respondents as variables. Five respondents per item is considered the minimum necessary to perform a potentially stable factor analysis. Therefore, the first step in the factor analysis was to examine the Kaiser-Mayer-Olkin measure of sampling adequacy (MSA) to eliminate dissimilar items that would not load well together. An unrestricted factor analysis of the 67 items was run, and a criterion of less than .6 was used to eliminate items of lower (than "mediocre") sampling adequacy (Kaiser, 1974). Following this process, the 67 items (with MSA = .66) were reduced to an improved set of 39 items (MSA = .85). Thirty-nine items for 188 respondents approximates the necessary five items per respondent for a viable factor analysis.

An unrestricted principal components analysis (Dunteman, 1989) with a varimax rotation was performed on the 39 remaining items, resulting in nine factors with eigenvalues greater than one (>1.0). Based on an examination of the factor scree plot and the percent of variance accounted for by each factor, the analysis was repeated with a restriction to four factors, to account for greater than 50% of the variance. Five items were deleted from this new 4-factor solution due to low ($<.40$) factor loadings or loading (comparably) on more than one factor. The 34-item principal components factor analysis is presented in Table 2, with factor loadings greater than .40 underlined. These analyses support the notion of four distinct factors, accounting for 53% of the total variance.

The four factors were named for the concept suggested by each cluster of items (see Table 2). The first factor, Somatic Concerns, consisted of 14 items related to physical considerations with a social-emotional component, resulting from the

woman's cancer experience. Factor 2, Spiritual/Philosophical View of Life, consisted of 11 items that reflected an increased insight and appreciation for life since the illness. Factor 3, Fitness, consisted of 5 items relating to exercise behavior and beliefs. Four items loaded on Factor 4, Social Support, reflecting a need for support and a desire to be of service to others.

As presented in Table 3, the physical domain was represented by the most items both before and after the factor analysis (35 and 17, respectively). Further, the physical domain split into two factors during analysis—one representing fitness behaviors and beliefs, and the other emphasizing somatic issues with a psychosocial component. Items in the physical domain factors came from both the psychological and social domains. The psychological domain began and ended with the fewest items (9 and 3, respectively), with the three remaining items shifting to either the physical or spiritual domains. Interestingly, the spiritual domain retained the largest number of original items, with 7 of the 11 spiritual items loading on one factor, along with some items from the social and psychological domains. In all, 33 items were deleted, resulting in a 34-item scale consisting of four factors that represented all four of the Ferrell domains, but with several domains conceptually overlapping rather than being distinctly separate (Wyatt & Friedman, 1996b).

Subscale Reliabilities

Internal consistency estimates were calculated for each of the four factors (subscales) using Cronbach's alpha. Subscale composite scores were computed as the average of individual item scores on that subscale. Reliabilities of the four subscales ranged from .87 to .92. These results are summarized at the bottom of Table 2. A correlation matrix of the LTQL subscales is presented in Table 4. A minimum p -value of .008 was used to determine significance, to correct for multiple correlations ($.05 \div 6 = .008$). The significant interscale correlations suggest that the subscales all measure components of an underlying quality of life construct. Test-retest reliability was not done due to the lack of repeated questionnaire administration.

Content Validity

Content validity of the LTQL items was initially assessed by interrater agreement on subscale items derived from focus group coding categories. Content validity was further supported by conceptual congruence between the four subscales of the LTQL and Ferrell's original four quality of life domains. As illustrated in Table 3, the four Ferrell Domains were retained, but individual items were rearranged during factor analysis, resulting in the integration of psychological items into other domains.

Concurrent Validity

Concurrent validity was assessed by comparing the LTQL with the CaRES, a commonly used measure of quality of life. A correlation matrix of the LTQL and CaRES subscales is presented in Table 5. A minimum p -value of .002 was used to

TABLE 2. Factor Loadings and Reliabilities

| Item # | Factor Loadings | | | | Communalities 5 |
|--|--------------------------|------------------------|--------------|------------------------|--------------------|
| | Somatic Concerns 1 | Phil/Spir View 2 | Fitness 3 | Social Support 4 | |
| Somatic concerns (Factor 1) | | | | | |
| 44 Difficulty accepting body | .764 | .034 | .021 | -.043 | .588 |
| 11 Self-conscious about body | .736 | -.078 | .753 | .086 | .561 |
| 37 Dissatisfied with look | .730 | -.001 | .098 | .105 | .554 |
| 46 Social life less since CA | .712 | .354 | .077 | -.041 | .516 |
| 55 Distressed with pain | .665 | .070 | .023 | -.181 | .481 |
| 24 Continue to have pain | .658 | .020 | .074 | -.217 | .486 |
| 47 Experienced pain | .645 | .081 | .061 | -.152 | .449 |
| 71 Have had to adjust exercising | .641 | -.276 | .086 | -.120 | .510 |
| 52 Numbness or tingling | .635 | .019 | -.036 | -.306 | .499 |
| 16 Difficulty finding clothing | .600 | -.191 | .216 | -.011 | .444 |
| 07 Satisfied with my body | .569 | .207 | .296 | .144 | .476 |
| 10 Susceptible to illness | .550 | -.084 | .068 | -.010 | .315 |
| 39 Eyesight worse | .506 | -.006 | -.126 | -.191 | .309 |
| 15 Raise arm or foot since Tx | .458 | .103 | .046 | -.057 | .226 |
| Philosophical/spiritual view of life (Factor 2) | | | | | |
| 06 Guiding energy | .051 | .756 | .121 | .034 | .590 |
| 48 Inner direction helps me | .022 | .744 | .112 | .141 | .588 |
| 14 Follow inner voice | .026 | .718 | .133 | -.010 | .534 |
| 30 Receive subtle cues | .023 | .716 | .175 | .158 | .569 |
| 13 Appreciate time with family/friends | -.084 | .701 | .153 | -.052 | .504 |
| 23 I have intuitive experiences that reassures me about health care choices | .024 | .631 | .181 | .125 | .448 |

(Continued)

(Continued)

| Item # | Factor Loadings | | | | |
|---|--------------------------|------------------------|--------------|------------------------|--------------------|
| | Somatic Concerns 1 | Phil/Spir View 2 | Fitness 3 | Social Support 4 | Communalities 5 |
| Philosophical/spiritual view of life (Factor 2) (Continued) | | | | | |
| 38 Notice things in nature | -.082 | .605 | .067 | .193 | .415 |
| 49 Become closer to family/friends | .020 | .586 | .100 | .122 | .369 |
| 53 Don't take things for granted | -.043 | .568 | -.010 | .187 | -.360 |
| 03 Better idea about serious illness | -.226 | .542 | .167 | .004 | -.373 |
| 35 Sympathetic with major illness | -.053 | .479 | .118 | .020 | -.247 |
| Fitness (Factor 3) | | | | | |
| 69 Exercise decreases fatigue | .149 | .180 | .890 | .039 | .849 |
| 70 Exercise helps me feel energetic | .152 | .225 | .854 | .001 | .803 |
| 67 Exercise helps me feel health | .093 | .210 | .852 | .072 | .784 |
| 68 I exercise more frequently | .120 | .264 | .801 | .100 | .737 |
| 33 Exercise so less likely to get CA | .131 | .218 | .740 | .161 | .639 |
| Social support (Factor 4) | | | | | |
| 56 Support, understanding to offer | .102 | .167 | .147 | .872 | -.821 |
| 09 Would like to be resource person | -.143 | .207 | .104 | .838 | -.777 |
| 01 Could be helpful to others | .034 | .186 | .036 | .794 | .669 |
| 54 Beneficial to others | -.233 | .179 | .059 | .718 | .606 |
| Eigenvalue | 6.988 | 6.522 | 2.440 | 2.160 | |
| % Variance | 20.6 | 19.2 | 7.2 | 6.4 | |
| Mean interitem correlation | .37 | .89 | .70 | .64 | |
| Alpha coefficient | .89 | .87 | .92 | .88 | |

Factor loadings > .040 are underlined.

TABLE 3. Number of LTOL Items Before and After Factor Analysis, by Domain

| Original Domain and Categories | Number of Items | | Resulting Factors |
|---|-----------------|-------|-------------------------|
| | Before | After | |
| Physical | 35 | 17 | Somatic Concerns |
| Eating habits (0 items retained) | 6 | 0 | (14 items) |
| Body image (4 items to somatic) | 6 | 4 | |
| Apparel (2 items to somatic) | 5 | 2 | Fitness |
| Pain (3 items to somatic) | 7 | 3 | (5 items) |
| Exercise (1 item to somatic; 5 items to fitness) | 6 | 6 | |
| Change in senses (2 items to somatic) | 5 | 2 | |
| Social | 12 | 6 | |
| Change in social support (1 item to somatic; * 1 item to spirit/phil; 2 items to social) | 7 | 4 | Social Support |
| Desire to be of service to others (2 items to social) | 3 | 2 | (4 items) |
| Relationships with health-care providers (0 items retained) | 2 | 0 | |
| Psychological | 9 | 3 | N/A |
| Perceived susceptibility to cancer (1 item to somatic) | 4 | 1 | |
| Change in perception of health and illness (2 items to spirit/phil) | 5 | 2 | |
| Spiritual | 11 | 7 | Spiritual/Philosophical |
| Spiritual guidance for health decisions (5 items to spirit/phil) | 6 | 5 | (11 items) |
| Change in philosophical view of live (3 items to spirit/phil) | 5 | 3 | |
| Total | 67 | 34 | |

TABLE 4. Correlation Matrix for LTOL Subscales

| Subscales | Subscales | | |
|------------------------------|------------------|---------------------|---------|
| | Somatic Concerns | Spiritual/Phil View | Fitness |
| Spiritual/Philosophical View | .095 | | |
| Fitness | .236** | .371** | |
| Social Support | .230** | .3619* | .198* |

* $p \leq .008$ (2 tailed). ** $p \leq .001$ (2 tailed).

determine significance, to correct for multiple correlations ($.05 \div 30 = .002$). The somatic concerns factor was significantly correlated with all of the CaRES subscales. Fitness was significantly correlated with the CaRES physical subscale. Finally, the total LTQL score was highly correlated with all CaRES subscales (except marital), and with the CaRES total score.

Construct Validity

Construct validity was assessed by one-way analyses of variance, comparing differences between subscale means according to demographic and health status

TABLE 5. Correlation Matrix for LTOL & CaRES Subscales

| | LTQL | | | | Total |
|--------------|--------------|----------------|--------------|-------------|--------|
| | Somatic 1 | Spir/Phil 2 | Fitness 3 | Social 4 | |
| CaRES | | | | | |
| Physical | .728** | -.049 | .296** | -.098 | .445** |
| Medical | .407** | .037 | .076 | -.018 | .266** |
| Psychosocial | .741** | -.051 | .151 | .203 | .380** |
| Sexual | .488** | -.108 | .267 | -.077 | .295* |
| Marital | .299** | .012 | .153 | -.199 | .157 |
| Total | .786** | -.047 | .234 | -.191 | .434** |

* $p \leq .002$ (2 tailed). ** $p \leq .001$ (2 tailed)

variables. Subscale composite scores differed as expected based on the women's characteristics.

As would be expected, among breast cancer survivors, mastectomy patients reported a lower quality of life on the somatic subscale and the total scale than did lumpectomy patients ($t = 3.73, p < .001$; $t = 2.38, p < .05$, respectively). Also, women currently experiencing a recurrence of any cancer reported higher somatic concerns and lower overall quality of life than those not currently experiencing a recurrence ($t = 4.65, p < .001$; $t = 1.95, p < .05$, respectively). Further, those with the longest survival time (11 or more years) reported lower quality of life than did women of shorter survival time on somatic concerns ($t = 2.74, p < .05$). While this may appear counter-intuitive, it should be noted that length of survival was significantly related to recurrence status, with the longer-term survivors more likely to have experienced a recurrence, either currently or previously.

Lumpectomy patients reported significantly higher scores on the fitness subscale than did breast cancer survivors who received mastectomies ($t = 2.78, p < .05$). In the whole sample, the youngest women (aged 22 to 39) reported lower quality of life than did the older women ($t = 2.18, p < .05$), on spiritual/philosophical views of life. On the social support subscale, women who had never experienced a recurrence reported significantly lower support than those experiencing a current recurrence ($t = 2.18, p < .05$). As such, the longer-term survivors (being more likely to have experienced a recurrence) reported significantly higher levels of social support than shorter-term survivors ($t = 2.10, p < .05$).

Descriptive Statistics of LTQL Subscales

The LTQL subscale means ranged from .71 to 2.32 (see Table 6). Subscale means on the CaRES were lower and less variable, ranging from .40 to 1.27. A subscale mean of 2 on either instrument indicated that the subscale, reflecting a concern or change since the cancer, applied to the participant "a fair amount." A subscale mean of 1 signified that the subscale applied "a little."

Two subscales of the LTQL (fitness and social support) had mean scores of greater than 2 (2.05 and 2.32 respectively), with over 58% and 67% of respondents

TABLE 6. Descriptive Statistics of LTQL and CaRES Subscales

| | <i>N</i> | Mean | <i>SD</i> | Range | % ≥ 2 Responding |
|-------------------------|----------|------|-----------|---------|-----------------------|
| LTQL | | | | | |
| Somatic concerns | 187 | .71 | .67 | 0-3.29 | 7.5% |
| Spiritual/philosophical | 187 | 1.59 | .86 | 0-3.64 | 32.1% |
| Fitness | 186 | 2.05 | 1.16 | 0-4.00 | 57.5% |
| Social support | 187 | 2.32 | 1.10 | 0-4.00 | 67.4% |
| Total | 188 | 1.38 | .51 | 24-2.91 | 12.2% |
| CaRES | | | | | |
| Physical | 174 | .50 | .58 | 0-3.08 | 2.3% |
| Medical interaction | 168 | .40 | .59 | 0-2.91 | 3.0% |
| Psychosocial | 166 | .74 | .65 | 0-2.95 | 5.4% |
| Sexual | 109 | 1.27 | 1.09 | 0-4.00 | 30.3% |
| Marital | 126 | .55 | .70 | 0-3.40 | 5.6% |
| Total | 168 | .63 | .51 | 0-2.33 | 1.8% |

(respectively) scoring a 2 or higher on these subscales. On the spiritual/philosophical view of life subscale, 32% of the women scored 2 or higher. Both the range in scores on all four subscales and the variability of subscale means support the ability of the LTQL to measure differences between respondents in multiple areas of quality of life.

DISCUSSION

The results of this study support the potential of the LTQL to be a useful measure of quality of life in long-term female cancer survivors. An exploratory principal components factor analysis of the LTQL produced four distinct factors with factor loadings of greater than .40 and subscale reliabilities ranging from .87 to .92. These four factors are congruent with Ferrell's four theoretical domains of quality of life developed for women with breast cancer. Although the LTQL retained all four of the Ferrell domains of quality of life (physical, psychological, social, and spiritual) within one instrument, individual items reconfigured to demonstrate an overlapping of domains for the long-term female cancer survivor.

From the physical domain, two distinct factors emerged: Somatic Concerns and Fitness. Somatic Concerns included items from all of the physical domain categories except eating habits; this factor also included items from the social and psychological domains to demonstrate the overlap of domains, as opposed to the domains being mutually exclusive. The Somatic Concerns factor was the most global in terms of integrating items from other domains.

The Fitness factor concentrated upon exercise activities that could enhance a woman's resistance to a recurrence of cancer, and help maintain her health in general. The Social Support factor included items related to changes in a sense of support, and a desire to be of service to others. Unlike the CaRES, the LTQL did

not retain any items referring to women's relationship with their health-care providers. This may signify that earlier concerns focused upon quality or type of care may be greatly diminished for long-term survivors, who now feel a more personal control over their life and future health.

The Spiritual/Philosophical Views On Life (Spirit/Phil) factor did not contribute items to any other factor, but did include items from the social and psychological domains. Similar to the Somatic factor, it can be said that the Spirit/Phil factor is complex and integrated across life domains, rather than one that stands alone.

In summary, items written from the four original Ferrell domains were retained within the LTQL, but not as distinct factors. Most noticeably, the psychological domain was integrated into the Somatic and the Spirit/Phil factors, whereas in Ferrell's administration of her instrument (the QOL-CS), the psychological factor remained distinct and represented the lowest quality of life (Ferrell et al., 1995a; 1995b). On the LTQL, quality of life was reflected from lowest to highest by the four factors respectively: Social Support, Fitness, Spirit/Phil, and Somatic Concerns. In contrast, in the Ferrell instrument, quality of life ranged from lowest to highest in the following order: psychological, spiritual, social, and physical. On both Ferrell's QOL-CS and on the LTQL, the predominately physical area represented the highest quality of life, as measured by physical well-being and somatic concerns, respectively. The congruence between the LTQL subscales and Ferrell's four domains of quality of life support the content validity of the LTQL.

Concurrent validity was supported by correlations between the LTQL and the CaRES. The somatic subscale on the LTQL was highly correlated with all of the CaRES subscales and its total score. This high level of correlation would be expected, as the somatic subscale on the LTQL was a conglomerate of items from various life domains measured by the CaRES. However, because the CaRES does not assess the spiritual domain, the spiritual/philosophical subscale of the LTQL did not correlate with any of the CaRES subscales.

The fitness subscale on the LTQL demonstrated significant correlation with the physical subscale of the CaRES, which is consistent with the fact that both subscales assess physical factors. The social subscale of the LTQL might have been expected to correlate with the psychosocial subscale of the CaRES; however, on the LTQL, all of the psychological items clustered on either the somatic or spirit/phil subscales, while the remaining social items focused specifically on change in social support and desire to be of service to others. Further, the social support subscale of the LTQL did not correlate with the medical interaction subscale because all of the provider relationship items dropped out of the final LTQL instrument.

The total LTQL score correlated with the total CaRES score and most of the CaRES subscales, except for the marital subscale, which was not an area included on the LTQL. The CaRES total score correlated significantly with the LTQL's somatic subscale and the total scores. In conclusion, the overall correlation between the two instruments was high, with predictable subscale exceptions. However, the LTQL was more sensitive to long-term differences than was the CaRES.

Construct validity was supported by examining logical differences between subscale means according to demographic and health variables. The LTQL

distinguished differences in quality of life (on somatic concerns and fitness) in lumpectomy versus mastectomy patients, with the mastectomy patients reporting lower quality of life in these areas, as would be expected. The LTQL also distinguished women currently experiencing a recurrence versus those who were not, on both the somatic and social support subscales. It is possible that women may be more likely to reach out for social support, and hence desire to give it back to others, when in a health crisis such as a cancer recurrence. The LTQL also found differences in quality of life, as measured by the somatic and social support subscales, according to length of survivorship, which paralleled the differences according to recurrence status. Finally, the youngest women reported lower quality of life in the spiritual/philosophical area than did their older counterparts, who may have developed more stable views on these introspective issues over the years. Overall, the LTQL seems to adequately distinguish long-term female cancer survivors across several dimensions.

Further research to refine the LTQL should include the assessment of additional external variables on which women would be expected to differ to further support construct validity. Factor stability should be assessed by performing a confirmatory factor analysis using an independent sample of participants. Test-retest reliability and discriminant validity should be confirmed. Testing of the LTQL with a sample more representative of minorities is also needed. In addition, the utility of the instrument with samples including men should be examined. When further testing of this instrument is completed, the LTQL may prove useful in studying long-term cancer survivors longitudinally, to assess changes in quality of life over time. The overlapping of life domains in the LTQL subscales may provide clues as to how to best intervene with the long-term survivor. The LTQL could also be used as a preintervention or needs-assessment instrument, and finally, as a postintervention evaluation tool for programs targeting long-term female survivors.

In conclusion, quality of life research to date has used either single dimension instruments or multidimensional measures (often omitting the spiritual domain) that have only recently begun to be tested with long-term survivors. This current research built upon critiques in the literature, and extended the Ferrell model by utilizing the four domains in an instrument specifically designed for long-term female survivors. Overall, instrument development for the long-term cancer survivor needs a holistic focus that goes beyond the physical and psychosocial domains to include areas such as spiritual, existential, and philosophical issues.

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Development and testing of a quality of life model for long-term female cancer survivors

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This research resulted in the evolution of a model depicting the quality of life of long-term female cancer survivors. The foundation for this model's development was Ferrell's (1993) breast cancer model, which incorporates physical, social, psychological and spiritual domains of life. The Ferrell model was adapted following focus-group discussions with 11 long-term female cancer survivors. The adjusted model included new categories, within each of Ferrell's initial domains, that were specific to the focus group participants. Administration of a new instrument, the Long-Term Quality of Life (LTQL), to 187 long-term female cancer survivors produced a final model that included the interaction of all four domains in six major concepts of quality of life. This new model, which reflects the complexity of life in long-term female cancer survivors, may be useful to health professionals in designing interventions to meet the unique needs of these women.

Key words: conceptual models; female cancers; long-term survivors; quality of life.

Introduction

Currently, there are six million Americans alive with a history of cancer. By the 21st century, overall survival rates are estimated to be well above the current 54%.¹ Long-term survivors, however, remain an understudied group. As increasingly more people live for extended periods of time, an examination of their concerns, attitudes and adjustments over time poses a challenge to oncology nursing. As the survival

rate for women likewise improves, female cancer survivors may experience unique changes in quality of life, as the cancer and treatment often affect areas associated with gender identity.

In understanding and addressing the needs and experiences of long-term female cancer survivors, a model or cluster of concepts encompassing quality of life would prove useful. However, there is not complete agreement over what constitutes the dimensions of quality of life,² nor about which concepts are most applicable or salient for female long-term survivors. Any comprehensive framework of quality of life should include current, ongoing and unresolved issues and concerns from the major areas of a woman's life (i.e., physical, social, psychological and spiritual). To date, there is no inclusive quality of life model for long-term cancer survivors in general or for female survivors specifically. Therefore, the purpose of this paper is to present the evolution of a holistic model of quality of life that was developed to understand the uniqueness of the long-term female cancer survivor. This newly-evolving model is expected to provide a state-of-the-art depiction of the issues relevant to long-term, female cancer survivorship and to serve as the basis for planning and evaluating interventions.

Long-term quality of life research

For this paper, long-term survival is defined as five years or longer since diagnosis. Five-year survival rates for all cancers combined currently exceed 50% for women.¹

Previous research on quality life

Padilla *et al.*² reviewed nursing research on quality of life from 1983-1991. In over 100 studies, investigators defined quality of life in terms of psychological,

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physical, social/interpersonal and financial/material well-being. Padilla *et al.* suggested that these conceptual and operational definitions of quality of life could be summarized in the form of a matrix, with quality of life attributes listed as row headings and subjective responses (or subcategories) defining column headings. Although this review integrated previous research into a conceptual model of quality of life, the spiritual dimension was not present in either the studies cited or in the model proposed.

Andersen³ reviewed psychological interventions to improve quality of life in women with gynecological cancer and proposed a conceptual model for predicting risk for psychological and behavioural morbidity in such patients. The model included four categories of information available at the time of diagnosis: (1) sociodemographic characteristics, (2) prior health status, (3) existing social networks and support and (4) other current stressors that were early moderators for the distress of diagnosis. This model was designed to predict short-term morbidity outcomes after recovery from cancer, rather than to address quality of life in long-term survivors or offer an inclusive model of quality of life.

Existing models of quality of life

Whereas many articles on short-term quality of life are purely descriptive or meta-analytical in nature, others report empirical studies based upon a theoretical framework. Northouse⁴ followed breast cancer patients and their husbands for 18 months post-surgery to assess changes in psychosocial adjustment over time. The theoretical framework behind this study was Minuchin's family systems theory, which underscored the need to assess the impact of illness on patients and spouses and to assess the effects of illness over time. Additionally, psychosocial adjustment was viewed as a multidimensional construct that included a positive balance of mood states, an absence of extreme psychiatric distress, and an ability to function in work, family and social roles. Northouse concluded that her findings supported viewing the impact of cancer on patients and husbands from a family systems framework. Although this model acknowledged the importance of social systems on quality of life, it did not directly address physical or spiritual issues of the individual.

In another study of quality of life in cancer patients, Rieker, Clark and Fogelberg⁵ examined patient and family perceptions about quality of life after experimental biological therapy for cancer (e.g., interleukin-2 plus chemotherapy). Quality of life was considered

to be a multidimensional construct consisting of a minimum of four areas: functional status (the ability to perform activities normal for age-adjusted populations), disease- and treatment-related symptoms (physical symptoms), psychological functioning (degree of distress) and social functioning (disruption of normal social activities). Other aspects of quality of life included relationship impact, sexual satisfaction and financial burden. Although the investigators suggested a multidimensional framework for quality of life in cancer patients, their model was incomplete in that it focused heavily on physical aspects, to the exclusion of a spiritual component.

The Cancer Rehabilitation Evaluation System—Short Form (CaRES-SF) was developed over the past several years and has been widely used to measure quality of life in short-term cancer survivors.⁶ The CaRES was originally based on a multidimensional conceptualization of quality of life that includes five concepts: physical, psychosocial, medical interaction, marital and sexual issues. Recent research⁷ found that 13 months after surgery for breast cancer, scores on the CaRES dropped to lower levels, indicating either that quality of life had improved, or that the CaRES was not sensitive to quality of life issues in longer-term survivors. The CaRES also lacks a spiritual dimension of quality of life, which might be particularly important for long-term cancer survivors, who are often in later developmental stages of life when spiritual issues become more salient.⁸ Although the current literature has contributed greatly to quality of life knowledge, researchers have continued to struggle with a conceptualization of this critical area to cancer survivors.

To date, the literature suggests a cluster of psychosocial and physical variables that must be included in any model of quality of life. However, a crystallization of exactly which psychological, social and physical variables are key, and an exploration of spiritual variables to round out or complete the model, are lacking. In developing a comprehensive model, it is necessary to test various concepts and allow the model to evolve until it stabilizes consistently around a core of essential concepts.

Conceptual framework

At least one team of investigators has addressed the need for a comprehensive conceptual framework for quality of life in cancer research. In 1985, Padilla and Grant developed a fairly inclusive multidimensional conceptualization of quality of life in cancer patients through three well-defined concepts: psychological

well-being, physical well-being and symptom control. In a second study,⁹ this model was adapted to fit colostomy patients, the majority of whom had cancer. This second model included six concepts of quality of life: psychological well-being, physical well-being, body image, surgical response to diagnosis/treatment (ability to resume sexual activity and the management of pain), nutritional response to diagnosis/treatment and social concerns.

Subsequently, Padilla and colleagues integrated many of their previously identified variables of quality of life into a concise conceptual model.¹⁰ From interviews with 41 cancer patients with chronic pain, they derived three content categories of quality of life: physical well-being, psychological well-being and interpersonal well-being. However, the Padilla *et al.*¹⁰ model, although more comprehensive than single-variable conceptualizations, still lacked the spiritual component of a more holistic model.

In 1992, Grant and associates¹¹ proposed a conceptual model of quality of life that elaborated on the bio-psycho-social framework¹⁰ by adding the domain of spirituality. This holistic conceptualization of the domains of quality of life, with the addition of the spiritual component, might also apply to long-term survivors of illness.

Ferrell¹² suggested the application of the physical-psycho-social-spiritual framework to breast cancer survivors. The holistic Ferrell model, upon which the current study is based, consists of four domains of quality of life (Figure 1): (1) physical well-being, encompassing areas such as symptoms associated with surgery, limited mobility and side effects of combination therapy of

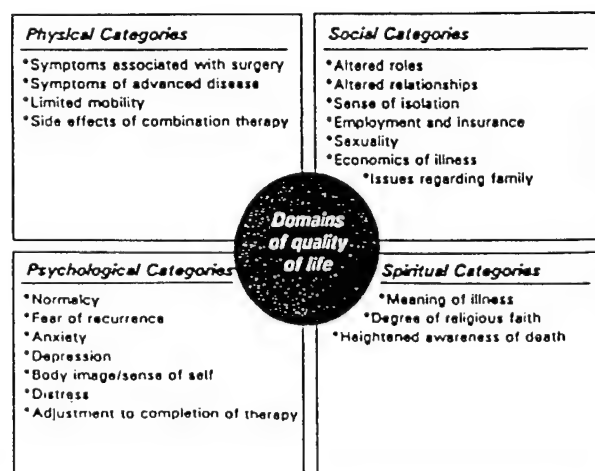
combination therapy; (2) psychological well-being, covering concerns such as fear of recurrence, anxiety, depression, normalcy and body image; (3) social concerns, including altered roles and relationships, sense of isolation, employment and insurance and sexuality; and (4) spiritual well-being, addressing the meaning of illness, degree of religious faith and heightened awareness of death as a result of the cancer. Ferrell suggests that these four domains of quality of life are impacted by the experience of breast cancer and its treatment.

Methods

The current study contributed to the evolution of a comprehensive quality of life model by testing the four basic domains of the Ferrell model on a sample of long-term, female cancer survivors. The structure, subcategories within domains, and interrelationships among domains, were adapted to construct a holistic model specific to long-term survivors. This study employed both qualitative and quantitative methods to modify and advance the Ferrell model of quality of life into a new, evolving model applicable to long-term female cancer survivors.

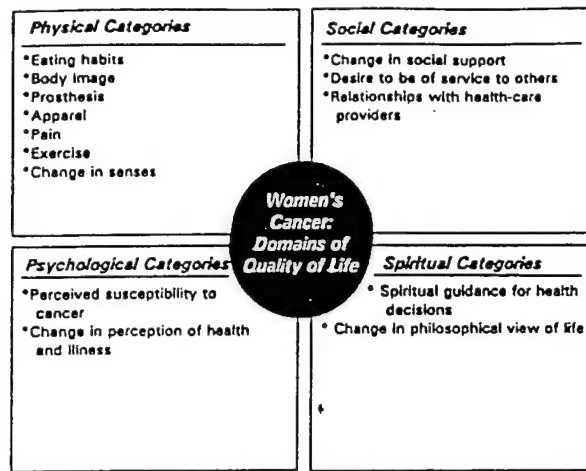
The two-step research process began with qualitative analyses of focus groups involving 11 women.¹⁴ The second step entailed quantitative analyses of a new instrument, the Long-Term Quality of Life (LTQL), developed from the focus group data, which was administered to a larger sample of 187 women.¹³ This research was approved by the Institutional Review Board at the participating institutions.

Figure 1. Ferrell's (1993) model of quality of life designed for short-term breast cancer survivors



Qualitative analyses of quality of life

Focus group discussions were conducted with 11 long-term female breast cancer survivors, some of whom had also had other cancers, to determine relevant issues from the women's perspective. Ferrell's domains were utilized to generate the focus group questions. During data analysis, participant's responses were grouped into 14 categories, which were organized according to the four Ferrell domains. Next, the 14 categories were conceptually assessed independent of the Ferrell framework to derive four major themes. And finally, the four identified themes were compared with the Ferrell domains to determine where content was unique and where overlaps occurred (see Wyatt *et al.*,¹⁴ for a more complete review of the focus group procedures and results).

Figure 2. Quality of life model for long-term survivors based on focus group coding categories

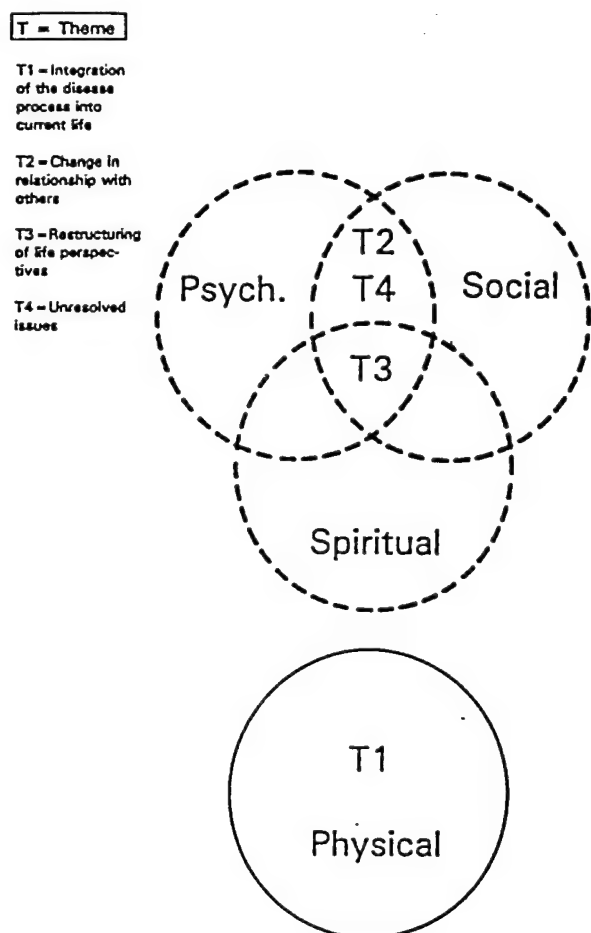
Quantitative analyses of quality of life

The Long-Term Quality of Life (LTQL) instrument was designed to quantitatively measure the categories illustrated in the model (Figure 2). This newly-developed instrument was administered to 187 female cancer survivors recruited through the tumor registry of a Midwestern hospital (see Table 1). Based upon the initial categories derived from the focus group data, five Likert scale items were written for each category, totaling 70 items. Following data collection, a factor analysis resulted in six statistically-generated factors (alphas ranging from 0.65–0.89), which were then compared to the original dimensions developed from the focus groups. Finally, the factors and themes were reconceptualized into the four Ferrell domains to provide a comparison with quality of life for the long-term survivor. For more complete information on sample selection, methods, participation

Table 1. Demographics of qualitative focus groups and quantitative LTQL group

| Variables | Qualitative data (n = 11) % | Quantitative data (n = 187) % |
|--|--------------------------------|----------------------------------|
| Employment | | |
| Unemployed | 73 | 73 |
| Employed | 27 | 37 |
| Part-Time | 18 | 39 |
| Full-Time | 9 | 60 |
| Marital Status | | |
| Married | 45 | 64 |
| Widowed | 27 | 17 |
| Divorced | 18 | 11 |
| Single | 9 | 8 |
| Treatment | | |
| Mastectomies | 100 | — |
| Tamoxifen | 9 | — |
| Chemotherapy | 63 | — |
| Chemotherapy and Tamoxifen | 18 | — |
| No adjuvant therapy | 9 | — |
| Surgery | — | 49.5 |
| Radiation | — | 3.8 |
| Chemotherapy | — | 0.5 |
| Hormonal | — | 1.1 |
| Surgery and radiation | — | 15.8 |
| Surgery and chemotherapy | — | 15.2 |
| Surgery and hormonal | — | 0.5 |
| Radiation and chemotherapy | — | 1.1 |
| Surgery and radiation and chemotherapy | — | 8.7 |
| Surgery and chemotherapy and hormonal | — | 1.1 |
| Surgery and radiation and chemo and hormonal | — | 1.1 |
| Age (range) | 61 (40–79) | 61 (22–92) |
| Years of survival (range) | 10 (5–14) | 8.42 (5–33) |

Figure 3. Interaction of quality of life domains based on thematic analysis of focus groups



rate and preliminary versions of the LTQL, please see Wyatt *et al.*¹³

Results

Qualitative results

The qualitative data from the focus groups were first analyzed into 14 coding categories, within the four Ferrell domains (see Figure 2), and then into four major themes. The final four themes depicted an overlap of all of Ferrell's major domains except the physical domain (see Figure 3).

The first theme isolated the physical domain from the other domains and was entitled 'Integration of the disease process into current life'. This theme included all of the coding categories from only the

physical domain: *body image, eating habits, exercise, pain, change in senses, prosthesis and change in apparel*. The second theme, 'Change in relationship with others', included categories from two domains: Social (*change in social support*) and psychological (*change in perception of health and illness*). Theme 3 was called 'Restructuring of life perspectives' and was derived from categories across three domains: Social (*desire to be of service to others*), psychological (*change in perception of health and illness*) and spiritual (*spiritual guidance for health decisions and change in philosophical view of life*). The final theme, 'Unresolved issues', included content from two domains: Social (*relationship with health-care providers*) and psychological (*perceived susceptibility to cancer*).

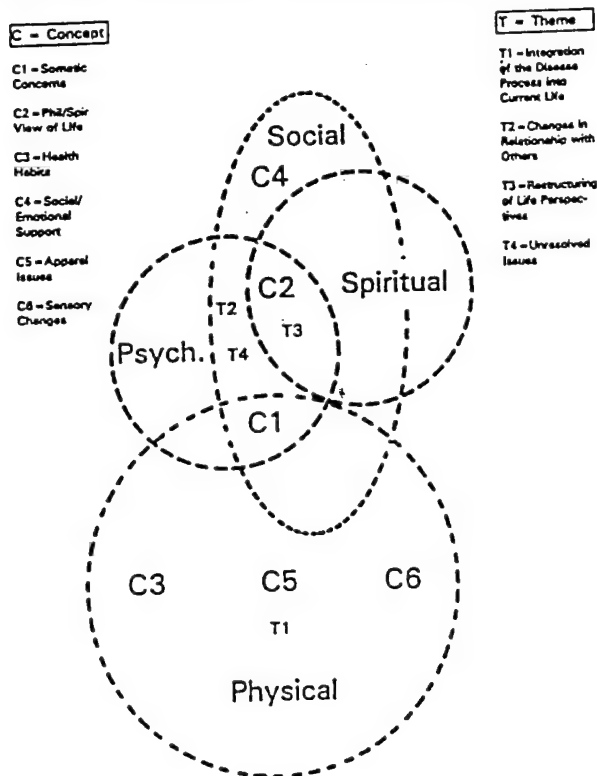
To summarize this model, the physical domain (Theme 1) was completely distinct from the other three. The social, psychological and spiritual domains interacted or overlapped in Themes 2, 3 and 4. In Themes 2 and 4, the interaction was between the social and psychological domains. Theme 3 represented a cross-section of three domains (social, psychological and spiritual). Thus, these themes depicted a new model of interconnected domains, as opposed to the separate, though interacting, domains suggested by Ferrell.¹²

Quantitative results

Factor analysis of the quantitative instrument revealed six factors congruent with the four themes from the focus groups. The six statistically-derived factors were converted to brief conceptual descriptions representing the items within each. Although there were many similarities, new and more complex interrelationships among domains emerged from the questionnaire analysis (see Figure 4).

The first factor/concept, 'Somatic Concerns', included categories from three domains: Physical (*body image, pain, change in senses*), social (*change in social support, relationship with health care providers*) and psychological (*perceived susceptibility to cancer*). Concept 2, 'Philosophical/Spiritual View of Life', encompassed categories from three domains: Social (*change in social support*), psychological (*change in perception of health and illness*) and spiritual (*change in philosophical view of life and spiritual guidance on decisions*). Concept 3, 'Health Habits', contained two categories solely from the physical domain: *exercise and eating habits*. Concept 4, 'Social/Emotional Support', was derived completely from the social domain categories: *change in social support and desire to be of service to others*. Concept 5, 'Apparel Issues',

Figure 4. Interaction and proportion of quality of life domains based on final concepts from the LTQL instrument (overlaid with focus group themes)



came strictly from the apparel category within the physical domain. Finally, Concept 6, 'Sensory Changes', also came from the physical domain and included two categories: *change in senses* and *pain*. Based on the administration of the LTQL, the three most significant concepts/factors, as evidenced by the highest means, were 'Social/Emotional Support', 'Health Habits', and 'Philosophical/Spiritual View of Life'.

In summary, Concepts 1 and 2 crossed domains. Concept 1 consisted of three domains (physical, psychological and social). Concept 2 fell within three overlapping domains (social, psychological and spiritual), which corresponded directly to Theme 3 from the focus groups. The quantitative findings resulted in increased complexity and integration of quality of life over the qualitative model derived from the focus groups alone. Concepts 3, 5 and 6 were derived solely from the physical domain (corresponding to Theme 1 from the focus groups) and one concept (Concept 4) was derived completely from the social domain.

The quantitatively-derived model represented increased complexity and integration of quality of life. The physical domain was no longer completely

isolated, as in the qualitative model and it also interacted with other domains. Two of the concepts, 'Somatic Concerns' and 'Philosophical/Spiritual View of Life', created overlap in three domains. All four domains interacted, with the most complex interactions occurring between the psychological, social and spiritual domains.

Summary of model evolution

The results of this study revealed a unique picture of quality of life for long-term female cancer survivors. The original Ferrell¹² model of quality of life depicted four discrete life domains that were affected by the experience of breast cancer. Within each domain, Ferrell suggested specific categories or issues that might be important to short-term breast cancer survivors (Figure 1). As reported in this study, focus groups with long-term, female cancer survivors led to tentative changes in the model's categories.

The interim model, after category analysis of the focus group data, proposed the same four domains in a similar format but contained different subcategories applicable to long-term, female cancer survivors (Figure 2). The second interim model, after theme analysis of the focus group data, produced a distinctly different model in which three of the domains overlapped or interacted with each other; only the physical domain remained separate and discrete. In this model, domains were represented by circles instead of squares to enhance visual conceptualization (Figure 3). Dotted lines in three domains signified an interaction among these domains. In addition, domain subcategories were replaced by underlying themes that suggested overlap of domains.

In the final model, developed after quantitative analysis of the LTQL instrument, focus group themes were replaced by concepts derived from the LTQL. All four life domains interacted to produce six major concepts, two of which were multidimensional (i.e., represented more than one domain). Again, dotted lines denoted the interaction of domains (Figure 4). The model evolved into a more complex representation of quality of life, in which domains overlapped as well as interacted. The areas of quality of life could no longer be separated into distinct domains as in the original models; rather, they combined into interrelated components to make up a total picture of quality of life. The final model advanced the original by broadening the population from breast cancer survivors to all female cancer survivors and by adapting the model to apply expressly to long-term survivors.

The major findings of this study supported the

construction of a conceptual model developed from the expressed concerns of focus group participants and subsequent testing through a quantitative format. All four of the original Ferrell (1993) domains were represented in the final model, though in different relationships to each other.

Discussion

This study suggests a model of quality of life similar to Ferrell's¹² but different in substantial ways. When reflecting on the foundation of the new model—the four major domains—it is noted that the physical domain appeared in four of the final factors. Due to its presence in four concepts, the physical domain was depicted as the largest circle in the final model. Quantitative results showed that the physical area was less significant to women, but its presence in four concepts suggests a foundation of other concerns still related to physical well-being. It seems that women held as less significant the physical areas they could not change (e.g., change in body image and adjustments needed in clothing selection to cover surgical areas or residual swelling). Instead, they reported difficulties in areas they potentially could control, such as changing diet and exercise patterns to promote health and longevity. These findings suggest that the long-term survivors experienced little regret over physical changes/adjustments, but they had found it difficult to incorporate recommended health habit changes. With this in mind, health professionals might plan interventions to assess knowledge deficits and provide resources to assist women in meeting their diet and exercise goals.

The social domain included three of the final concepts. The 'social/emotional support' concept had the highest percentage of endorsement, suggesting a strong social element is important for the long-term survivor. Nurses should be aware of these social support needs, and should include significant others, when designing interventions.

The psychological domain contributed to two of the final concepts. In both concepts, the psychological domain overlapped with the social domain and either the physical or spiritual domains. Nurses working with cancer survivors might be unable to separate the psychological from other issues and may, therefore, need to address them together. Women's somatic changes, their philosophical grounding, and how they feel and respond in their significant relationships would all need to be considered.

The spiritual domain, omitted in many other conceptualizations of quality of life but present in

Ferrell's¹² model, contributed to one of the major concepts identified from quantitative data. This concept also contained two other domains, demonstrating that spirituality is not isolated, but is inter-dependent upon other aspects of life. In addition, 'Philosophical/Spiritual View of Life' was rated the third highest in importance to the overall sample. This less tangible area could be addressed through professional education to increase nurses' comfort in discussing sensitive issues. Such education might be especially important in the realm of spirituality and philosophical view of life. Nurses should encourage women to share spiritual/philosophical concerns and fears, both in individual clinical interactions and with supportive peers and significant others. As suggested by the new quality of life model, spiritual concerns or conflicts (e.g., guiding forces in life, appreciation for life) should be incorporated into routine nursing assessment and interventions, to help women process and cope with these important issues.

Although based on both qualitative and quantitative data, this newly-developed model can be further tested and refined through replication, using this approach with a similar sample. This model could then be applied to other populations, e.g., men and/or survivors of other illnesses. Through replication and revision of this model with a variety of populations, a clearer definition of the quality of life will emerge to serve as a solid foundation for future research.

The complexity represented by the newly-designed model expresses quality of life of the long-term female survivor as a multidimensional interaction of life domains, stressing the importance of spiritual/philosophical issues, social support and behavioural health changes, while minimizing the past physical events of cancer. Such a model offers potential direction for nursing interventions with long-term survivors—one that emphasizes support for improvement of health habits and the exploration of philosophical and spiritual insecurities.

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Long-term female cancer survivors: quality of life issues and clinical implications

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The purpose of this research was to identify concerns and issues related to quality of life in long-term female cancer survivors and to discuss the implications of these issues for nursing. Data were collected by mailed questionnaire to 188 female long-term cancer survivors whose mean age was 61 years. Respondents were recruited through a Michigan tumor registry. The newly developed Long-Term Quality of Life (LTQL) instrument was used to measure quality of life in four domains: physical, psychological, social, and spiritual. We hypothesized that physical concerns would be minimal, whereas psychological, social, and spiritual areas would encompass salient issues. Our hypotheses were supported, with the lowest levels of quality of life found in the areas of spiritual/philosophical views, diet and exercise habits, and social/emotional support; the highest area of quality of life was physical, i.e., the absence of somatic concerns. Long-term survivors have resolved many of the physical concerns resulting from their illness and treatment. However, nursing

interventions can still improve quality of life in the psychological, social, and spiritual areas. A multipurpose support group for survivors is recommended, including "exercise partners" to support regular exercise, group discussions of spirituality and philosophical views of life, and community service activities with women's organizations and/or newly diagnosed women.

Key Words: Quality of life — Cancer survivors — Women.

Due to improved health care, survival rates continue to soar among cancer patients, and women are no exception to this phenomenon. Five-year cancer survivorship was expected to exceed 54% in 1995 (1). As women continue with their lives after cancer, nurses will encounter these survivors in diverse settings, including outpatient and community-based facilities. It is important for nursing to look anew at the needs of long-term survivors. Female cancer survivors may experience changes in multiple domains of life, i.e., physical, psychological, social, and spiritual areas. These long-term survivors are likely to have special concerns, needs, and strengths that continue many years after their initial diagnosis.

Although quality of life is often conceptualized as a multidimensional construct, there is not complete

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agreement in the literature as to what constitutes the specific dimensions of quality of life (2). Most research on quality of life among cancer patients has focused on the assessment of needs and issues within the psychosocial life domain, with several studies addressing physical concerns, and fewer tapping the spiritual domain. In addition, research is lacking on the assessment of quality of life in *long-term* cancer survivors. Because survivorship of adult cancers is a relatively new phenomenon, information about the long-term and delayed effects of cancer therapies on quality of life is sparse (3). This void in the literature is a problem in that it leaves nurses with little direction from which to base interventions for long-term survivors. Therefore, the purpose of the current study was to identify concerns and issues related to quality of life in long-term female cancer survivors (i.e., survivors of 5 or more years postdiagnosis) and to discuss the implications of these issues for nursing.

LITERATURE REVIEW

Physical Adjustment Studies

Loescher et al. (3) identified physiologic late effects of treatment, including decreased sexual and reproductive function; neurological, vascular, cardiac, pulmonary, urologic, and gastrointestinal problems; and future cancers. Young-McCaughan and Sexton (4) found a higher quality of life among breast cancer patients who exercised regularly when compared with women with breast cancer who did not exercise. A recent study assessing nutritional concerns of Reach to Recovery volunteers found that subjects wanted information on diets for cancer prevention, low-fat diets, weight reduction, and vitamin supplements (5).

Winningham and colleagues found physical activity programs to have positive effects on physical well-being and functional status (6,7). Others have included exercise in interventions with beneficial results for the participants, including increased leisure activity and improved mood (8).

Psychological Adjustment Studies

A majority of the quality of life research has focused on changes in psychological adjustment, with many studies assessing the effects of specific cancer treatments on psychological quality of life. Quigley (9) reviewed psychological consequences of adult survivors, including emotional consequences such as uncertainty, somatic and psychological distress, and decreased self-esteem and body image. Investigators have identified other psychological effects of cancer,

such as fear of recurrence and death, and distress related to physical compromise (10,11). Intervention programs to enhance quality of life in the psychological domain have included the addition of a caring partner "coach" to traditional cancer support groups (12), and support groups encouraging mutual support and the discussion of death and dying for breast cancer survivors (13). Spiegel (13) reported support group outcomes of reduced mood disturbance; phobia, and pain; improved coping responses; and increased survival time to twice as long as subjects in the control group.

Social Adjustment Studies

Several areas of social adjustment have been identified as important after cancer including marital and relationship stress (9,14), problems with sexuality (9,15), isolation, changes in social support (11), and problems and discrimination related to employment and insurance (9,11). Researchers have also examined the combined psychosocial effects and adaptation over time, finding a decline in patients' mental health status longitudinally (16), and improvements in patients' mood and role functioning, but not improvements in level of distress up to 18 months postsurgery (17).

Samarel and Fawcett (12) reported positive initial findings from a pilot social intervention study, including increased social skills and support of the participants, contributing to continued adaptation. Clinical interventions to improve sexual functioning after gynecologic cancer have been reviewed in clinical, but not experimental, reports (18). Ferrans (19) found that support from friends was reaffirming; however, on the other hand, Wyatt et al. (20) found that some women felt forgotten by friends, because some friends tended to avoid them after their cancer diagnosis. Zacharias et al. (21) studied quality of life of gynecologic cancer patients and found that family relationships contributed most to their quality of life. Ferrans (19) also found that financial and insurance issue were of great concern. Many subjects found it impossible to obtain health insurance once they were diagnosed with cancer. Both Ferrans (19) and Wyatt et al. (20) cited new meaning for cancer survivors from volunteer work. Sharing their experience often led to a renewal of hope for themselves.

Spiritual Well-Being Studies

Although the topic of spirituality in nursing practice has been discussed in the literature, relatively little research has addressed the spiritual needs of

cancer patients or survivors. O'Connor et al. (22) found faith and social support of cancer survivors to be significantly related to the search for meaning in life. Mickley and Soeken (23) found that religiousness may be an important variable affecting both the spiritual and the psychological health of women with breast cancer, and that cultural differences may exist. Highfield (24) found that nurses inaccurately assessed their patients' spiritual health, although cancer patients reported a relatively high level of spiritual health, positively related to both age and physical well-being.

Multidomain Studies

Houts and colleagues (25) assessed unmet psychological, social, and economic needs of cancer survivors. Corney et al. (10) investigated emotional and informational needs of women who had undergone major surgery for gynecological cancer in the previous five years. Ganz et al. (26) assessed rehabilitation needs and quality of life in women with breast cancer, tapping five areas: physical, psychosocial, marital, sexual, and medical interaction. On all five factors, quality of life scores improved over time, with reported distress and concerns in the five areas falling to low values. O'Hare et al. (27) identified multiple unmet needs of black cancer patients, including unmet personal care and home activity needs.

Some intervention programs have targeted multiple areas of life in cancer survivors. Cain et al. (8) discussed a thematic counseling model that focused on information about cancer and positive health strategies such as progressive relaxation, diet, and exercise. The authors reported positive outcomes from the intervention, including such results as decreased depression and anxiety, fewer sexual difficulties, increased knowledge of the illness, increased participation in leisure activities, and improved relationships with caregivers.

Summary of Quality of Life Research

In summary, much research has assessed the effects of cancer on quality of life in cancer survivors. Intervention studies to improve quality of life for cancer survivors have focused on social support and the psychological and physical domains of life. Although the effects of such interventions have been generally positive, research on quality of life and appropriate interventions for *long-term* cancer patients, especially in the area of spirituality, is lacking and greatly needed.

THEORETICAL FRAMEWORK

The instrument developed for this study was based on Ferrell's (28) application of the physical-psychosocial-spiritual framework for breast cancer survivors. Ferrell's model consisted of four domains of quality of life: (a) physical well-being, encompassing areas such as symptoms associated with surgery, limited mobility, and side effects of combination therapy; (b) psychological well-being, covering concerns such as fear of recurrence, anxiety, depression, normalcy, and body image; (c) social concerns, including altered roles and relationships, sense of isolation, employment and insurance, and sexuality; and (d) spiritual well-being, addressing the meaning of illness, degree of religious faith, and heightened awareness of death as a result of the cancer.

The current study examined quality of life in long-term female cancer survivors. Quality of life was conceptualized, as per Ferrell (28), as a multidimensional construct including the physical, social, psychological, and spiritual domains of life. Although this study was exploratory in nature, focus groups with long-term survivors in a previous study (20) led the principal investigator to hypothesize that the physical concerns of subjects would be minimal, but that the psychological, social, and spiritual areas would still encompass salient issues for the women.

METHOD

Subjects

The subjects of this study were female cancer survivors ($n = 188$) identified through the tumor registry of a Michigan hospital. The majority of subjects were white (83%), married (64%), and not employed (73%). Fifteen percent had not graduated from high school, 27% were high school graduates, 37% had attended some college, and 22% had completed college or beyond. Ages ranged from 22 to 92, with a mean age of 61 years. More than half (58%) had survived breast cancer, 13% uterine cancer, with the rest representing other cancers affecting women. Length of survivorship ranged from 5 to 33 years, with a mean survivorship of 8.42 years.

Instrument

The instrument employed was the Long-Term Quality of Life (LTQL), a newly developed questionnaire designed to assess quality of life in long-term female cancer survivors (G. Wyatt et al., unpublished observations). Because this was the first testing of the

LTQL, it must be noted that this new instrument is in the developmental stage. Although the LTQL was designed using the Ferrell (28) model as a framework, the factor analysis grouped items in a manner that presented an interaction rather than a separateness of the original Ferrell domains. One unexpected aspect of the instrument analysis was that items addressing the psychological domain did not constitute a stable factor. As the instrument is further refined, new items, which more closely portray the psychological issues of long-term female survivors, will need to be generated and tested. Forty-six of the original 56 items were retained after factor and item analyses, resulting in four subscales: Somatic Concerns, Philosophical/Spiritual View of Life, Health Habits (Diet/Exercise), and Social/Emotional Support. Items are measured on a 5-point Likert scale, with 0 indicating low quality of life and 4 indicating high quality of life. The validity and reliability of the LTQL is reported in detail elsewhere (G. Wyatt et al., unpublished observations); however, subscale reliabilities ranged from 0.86 to 0.89.

Procedure

Female cancer survivors of 5 years or longer, identified through a Michigan tumor registry, were sent packets containing the LTQL instrument, demographic questions, and an explanatory letter. If a woman decided to participate in this study, she completed the questionnaires and returned them to the investigator in the enclosed addressed stamped envelope. Informed consent was detailed in the cover letter, and completion of the questionnaires was taken to signify consent to participate in the study, as per guidelines of the University Committee on Research Involving Human Subjects.

RESULTS

The four subscales will be discussed in this section in light of their content, scores, and comparisons among subgroups of subjects. See Table 1 for descriptive statistics of the LTQL subscales.

Somatic Concerns

The Somatic Concerns subscale included 15 items. This subscale pooled items related to bodily changes, and how physical changes associated with cancer had affected other aspects of subject's lives.

Somatic concerns consisted of the largest number of items and was an area of fairly high quality of life

TABLE 1. Descriptive Statistics of Long-Term Quality of Life Subscales

| Factor name | N | Raw mean | SD | Range |
|--------------------------------------|-----|----------|------|-----------|
| Somatic Concerns | 186 | 2.89 | 0.68 | 0.23-4.00 |
| Philosophical/Spiritual View of Life | 186 | 2.47 | 0.84 | 0.38-4.00 |
| Health Habits | 184 | 2.12 | 0.91 | 0.10-4.00 |
| Social/Emotional Support | 183 | 1.53 | 0.98 | 0.00-4.00 |

to the women. The mean subscale response was 2.89, with a range of 0.23 to 4.00.

Despite an overall high scale mean, several items had substantially lower mean scores. These items with lower means, signifying greater concerns or lower quality of life, related to body image and fear that their body would fail again with a recurrence of cancer. For example, the lowest-scoring item was "I would like my body to be like it was before my cancer." Another low-scoring item was "I fear my body/I will develop cancer again in the future." Higher quality of life was expressed by items asking about pain and whether the cancer had caused physical effects that altered subjects' social life, suggesting that these women were not bothered by many physical concerns or symptoms.

In addition, several subgroups of subjects reported significantly lower quality of life on Somatic Concerns than did other subgroups. Subjects in the 40- to 55-year-old age category had a lower quality of life on this subscale than the older or younger subjects. Furthermore, mastectomy patients had a lower quality of life on Somatic Concerns than did lumpectomy patients. Subjects currently experiencing a cancer recurrence also reported a lower quality of life in this area; those with a previous recurrence had a somewhat higher quality of life, and subjects who had never experienced a recurrence had scores reflecting the highest quality of life on Somatic Concerns. Finally, those with the longest survival time (11 or more years) indicated lower quality of life than did subjects of shorter survival. However, it should be noted that length of survival was significantly related to recurrence status, with the longer-term survivors more likely to have experienced a recurrence, either currently or previously.

Philosophical/Spiritual View

The Philosophical/Spiritual View of Life subscale included 13 items grouped around existential or philosophical life viewpoints. The mean response for

this subscale was 2.47, indicating a moderately high quality of life in the area of Spiritual/Philosophical View of Life. (Low quality of life scored in the 0-1 range, and high quality of life scored in the 3-4 range.)

The highest scoring items on the Spiritual/Philosophical subscale related to increased appreciation of life, time with family and friends, and new perceptions of serious illness (e.g., "I am more sympathetic with family/friends who have major illnesses, such as heart or kidney disease since my cancer"). Subjects indicated a lower quality of life on items relating to an inner direction or spiritual "security." Surprisingly, subjects only moderately endorsed the item "I have become closer with some family members/friends since having had cancer." The youngest subjects (ages 18-39) had lower quality of life on the Spiritual/Philosophical View subscale than did the older subjects.

Health Habits (Diet/Exercise)

The subscale entitled Health Habits (Diet/Exercise) included 10 items related to how diet and exercise are affected by cancer. Health habits were of greater concern than Spiritual/Philosophical View, the mean response being 2.12, with a range of 0.10-4.00.

The highest-scoring items in this scale related to behavioral dietary changes and the belief that a healthy diet would decrease subjects' chances of getting cancer again. The lowest item endorsement related to increased frequency of exercise and positive attitudes about exercise (e.g., "Regular exercise keeps me healthy, so I am less likely to get cancer again"). Subjects who had undergone mastectomy for breast cancer scored lower on Health Habits than did lumpectomy patients.

Social/Emotional Support

The final subscale consisting of seven items was Social/Emotional Support, and dealt with providing and receiving support. This subscale had a mean of 1.53, reflecting the lowest quality of life of all the subscales (range on the subscale was 0 for low quality of life to a high of 4).

The majority of the Social/Emotional Support items tapped a willingness and desire to be of service and exchange support with other cancer survivors. Although the women moderately felt they could be helpful to recently diagnosed cancer patients, they were currently providing such support only "a little."

Several subgroups of subjects scored differentially on the Social/Emotional Support subscale. Subjects in the 40-55-year-old age category scored highest on Social Support. Women who had stage 2 or 3 cancer also scored higher on Social/Emotional Support. Interestingly, those who had never had a recurrence of cancer scored lower on Social Support, with the subjects currently experiencing a recurrence reporting the highest level of support or social interest. Finally, non-breast cancer survivors reported lower social support than their breast cancer counterparts.

CONCLUSIONS AND IMPLICATIONS

The areas of greatest potential concern to these long-term survivors (in order of significance) were Social/Emotional Support, then Health Habits (Diet/Exercise), followed by Spiritual/Philosophical View of Life, and finally, as least salient, Somatic Concerns.

Somatic Concerns

The high quality of life represented by the somatic subscale suggests that the physical domain remains only a residual issue to long-term survivors' quality of life. The women in this study appear to have worked through and/or resolved many of the initial concerns about their bodies resulting from their illness and treatment. This finding suggests the need for nursing to address such concerns earlier in the survival process and to determine at which point in the survival trajectory women would most benefit from intervention in the complex area of somatic concerns. Obviously, survivors who are experiencing a recurrence of cancer will need more support with their physical well-being.

Spiritual/Philosophical

It is clear that Spiritual/Philosophical issues appear to remain on the women's minds in a more significant way than do Somatic Concerns. The items of this scale were worded without specific religious reference, but in a more existential manner. The Philosophical/Spiritual results suggest that nurses should be educated in, and become more comfortable with, a wide variety of existential, spiritual, and philosophical issues, so that they are able to discuss such issues with patients. Educational programs could increase nurses' acceptance of views and beliefs that may be different from their own, and teach a tolerance of belief systems that are significant to patients' quality of life (29). Diversity must begin to cut across more than cultural barriers, but also conceptual bar-

riers, to incorporate belief systems that serve as a support to patients during difficult times in their lives (30,23). Nurses should be able to discuss sensitive issues, which may be especially important in the area of spiritual/existential perceptions, and encourage women to share their spiritual experiences as well as their concerns, both in one-on-one interactions and in support groups. The results of this study also indicate that younger survivors should be especially encouraged to participate in such spiritual discussions, to help them address existential concerns brought on prematurely by their cancer.

Health Habits (Diet/Exercise)

It appears that issues related to diet and especially exercise may be unresolved for many women, and trouble them long after their cancer diagnosis. This is an area of life in which women could exert greater control, but they appear to be having difficulty doing so. Although the women in this study seemed to believe that a healthy diet is associated with increased stamina and greater resistance to a recurrence of cancer, they were less convinced about the benefits of exercise, possibly due to, or resulting in, a lack of regular exercise. Because changes in exercise and diet are often difficult to initiate and maintain, specific support groups that incorporate a partner for exercise and diet could be beneficial in promoting and adapting to these changes.

Social/Emotional Support

Finally, the Social/Emotional Support area is one of the major concerns to long-term survivors. Women believed that they could be of help to other newly diagnosed women with cancer, but also expressed a lack of support in their own lives, e.g., no new friendships, and no improvement in existing relationships. These women are either not accessing support, or do not see themselves as benefiting from support. Perhaps a new type of support group for the long-term survivor could address this issue, one that paired newly diagnosed women and longer-term survivors together. This would meet the interest of the long-term survivor to be of service to other women. Many of the women in this study felt that they had something to offer other survivors but were not actualizing their potential. Women could also be introduced to the idea of public speaking as another way of sharing their cancer experience with others. However, women may not see themselves as speakers and therefore may need support and encouragement to reach out with success in this way. The social/

emotional returns of public speaking would be potentially beneficial to both the survivors and to the audiences of women who hear their message.

Multidimensional Intervention

Finally, perhaps a combination of interventions would be most practical, i.e., a multipurpose support group addressing the most significant issues for the long-term survivor. This type of group might potentially combine the elements suggested previously, such as "exercise and diet partners," group discussions of spiritual and philosophical views, and community service activities with women's organizations and/or newly diagnosed patients.

DISCUSSION

The results of this preliminary study using a new instrument suggest that quality of life for female cancer survivors is not simply a "return to normal" 5 years after diagnosis, but rather the emergence of a "new" woman who has been able to put her physical changes into perspective and is now dealing more with relationships, existential issues, and the pursuit of health. Such shifts suggest developmental evolution from basic physiological concerns to more relational and spiritual needs (31). Nursing interventions, therefore, should address these adjustment issues throughout the stages of survival to help women anticipate changes and experience improved quality of life. □

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**PSYCHOLOGICAL AND SEXUAL WELL-BEING,
PHILOSOPHICAL/SPIRITUAL VIEWS,
AND HEALTH HABITS
OF LONG-TERM CANCER SURVIVORS**

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The results of a survey on various aspects of quality of life for 191 women who were long-term cancer survivors are presented. We explored six areas—somatic concerns, health habits, psychological state, sexual satisfaction, social/emotional support giving, and philosophical/spiritual view—and whether differences existed in them among the women on the basis of age, educational level, income level, length of survival, location of residence (urban, suburban, or rural), cancer site, and whether a recurrence of the cancer had been experienced. Generally, the women reported good psychological states and relative satisfaction with their sexual lives. However, women who had experienced a recurrence of their cancer, were longer term survivors, or suffered from breast cancer all reported higher levels of somatic concerns. Women with higher levels of education or income and those who had had a recurrence of their cancer indicated a greater willingness to provide social and emotional support to other women newly diagnosed with cancer. Women who had a positive philosophical/spiritual outlook were more likely to have good health habits and be supportive of others. There was no statistically significant variation among the women in either health habits or psychological state for any of the factors considered.

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The diagnosis of cancer evokes far greater distress than most other diseases, regardless of prognosis (Stechlin & Beach, 1966; Vinokur et al., 1989). The distress begins with diagnosis and treatment, but it seems to continue and reverberate far beyond the treatment phase. Numerous authors have explored psychosocial adjustment and other issues of quality of life of patients in the early stages of cancer (de Haes & van Knippenberg, 1985; Ganz et al., 1989; Heim et al., 1987; Irvine et al., 1991; Koch & Hoog, 1986), but there is a dearth of information on long-term survivors and how they have adjusted and integrated their cancer experience into their current lives.

In their study of psychosocial adjustment in women who had survived 5 years after breast cancer and a control group of asymptomatic women, Vinokur et al. (1989) found that the breast cancer survivors manifested practically the same level of psychosocial adjustment as the control group did. In a recent study on problems of social reintegration of long-term cancer survivors in The Netherlands, Greaves-Otte et al. (1991) found the psychological well-being of the respondents to be low in comparison with the overall Dutch population. Numerous researchers have identified psychosocial factors associated with immediate psychological adaptation to cancer (Krouse, 1981; Schonfield, 1972; Taylor et al., 1985; Watson et al., 1984), but few have examined the potential influence of these factors on response to cancer over time (Ell et al., 1989). Even less information is available on the long-term psychosocial adjustment of the older patient with cancer. This gap in the literature is distressing, in light of the fact that the vast majority of cancers occur in people over the age of 55 (American Cancer Society, 1994).

Advances in cancer treatment have led to prolonged survival, and cancer as an illness has shifted from an acute disease to a chronic disease, for which long-term treatment and follow-up care are common and necessary (Ganz, 1990). The American Cancer Society (1994) has reported that survival rates are high among women with cancer, particularly those with breast cancer, the most frequently occurring cancer among women. The 5-year survival rate for breast cancer has risen from 78% in the 1940s to 93% in 1994, while data based on women diagnosed in the early 1970s indicate a long-term breast cancer survival rate of about 50%. Because of the increasing number of long-term cancer survivors, a clear understanding of this population is needed.

We conducted a survey on the psychological and sexual well-being, philosophical/spiritual views, and health habits of women who were long-term cancer survivors. Specifically, we explored six areas—somatic concerns, health habits, psychological state, sexual satisfaction, social/emotional support giving, and philosophical/spiritual view—and whether differences existed in them among the women on the basis of age, educa-

tional level, income level, length of survival, location of residence (urban, suburban, or rural), cancer site, and whether a recurrence of the cancer had been experienced.

METHOD

Sample

The target population was women who were long-term survivors of cancer. Because there is no universal definition of long-term survival, for the purposes of this study, we considered long-term survivorship to be 5 years or more from the date of first diagnosis of cancer. Three hundred fifty qualifying women were identified through the tumor registry of a hospital located in southern lower Michigan. One hundred ninety-one (55%) of these women agreed to participate in the study. The majority of the women were white (92.7%), married (63.7%), and not employed (63.7%). Their educational experience ranged from no high school diploma (14.7%), to completion of high school (27.7%), to completion of some college (36.6%), to bachelor's degree (11.5%), to graduate or professional degree (9.4%). The women's ages ranged from 22 to 92 years, with an average of 60.6 years. The most frequently reported cancer was breast cancer (57.6%), followed by uterine cancer (11.5%), colorectal cancer (5.2%), ovarian cancer (3.2%), lymphoma (2.1%), lung cancer (1.6%), and other (18.8%). Recurrence of cancer had been experienced by 16.5% of the women.

Instrument

We used two questionnaires to elicit data from the women. Somatic concerns, health habits, social/emotional support giving, and philosophical/spiritual view were assessed using components of the Long-Term Quality of Life (LTQL) instrument developed by Wyatt et al. (unpublished manuscript). This instrument focuses on the domains of quality of life identified by Ferrell (1992), and its development was based on the results of studies of focus groups of women who were long-term cancer survivors.

The Somatic Concerns scale includes 14 items, such as "I have difficulty accepting my body since my cancer," "I feel more susceptible to other illnesses since having cancer," and "I continue to have pain since my cancer treatment." Health Habits is a 10-item scale that includes items such as "Since my cancer treatment, I exercise more frequently," "I eat more fruits and vegetables since my cancer diagnosis," and "I eat less fat and red meat since my cancer diagnosis." The 7-item Social/Emotional Support Giving scale contains items such as "I think that I have support and under-

standing to offer to other long term cancer survivors," "I would like to be a resource person to others who have recently been diagnosed with cancer," and "I currently provide emotional support to people newly diagnosed with cancer." Philosophical/Spiritual View is a 12-item scale that includes items such as "I feel a guiding energy in my life which has my best interest in mind," "Since having had cancer I have a greater appreciation for everyday life," and "Since having had cancer, I tend to notice things in nature more, such as sunsets, raindrops and spring flowers." A complete description of the development of the LTQL, including reliability and validity testing, has been provided by Wyatt et al. (unpublished manuscript).

Psychological state and sexual satisfaction were measured with scales taken from the Cancer Rehabilitation Evaluation System (CARES; Ganz et al., 1990). The CARES is an established instrument designed to measure cancer patients' adjustment in the physical, psychosocial, medical, marital, and sexual domains and has well-documented reliability and validity (Schag & Heinrich, 1990). However, because of its length and the fact that various segments focus on aspects of adjustment related to early treatment, we used only selected components in the present study. Typical items from the 8-item Sexual Satisfaction scale were "I do not feel sexually attractive," "I do not think that my partner is interested in having sex with me," and "I have difficulty becoming sexually aroused." The 9-item Psychological State scale includes items such as "I frequently feel overwhelmed by my emotions and feelings about the cancer," "I frequently feel upset," and "I frequently feel depressed."

Thus we used a total of six scales, with all items scored on a 5-point Likert-type scale on which subjects indicated the degree to which the item applied to them: *not at all* (0), *a little* (1), *a fair amount* (2), *much* (3), or *very much* (4). Some items were stated negatively in order to reduce acquiescence response set bias. These items were reverse-coded for the analysis, so that in every case a low score corresponded to a "positive" response. An additional section was included to elicit demographic information.

The questionnaires, along with an explanatory letter, were mailed to the women by the tumor registry, so that the confidentiality of the registry was maintained. If the women agreed to participate in the study, they returned the instruments to the investigators in a self-addressed, stamped envelope. The study was approved by the University Committee on Research Involving Human Subjects.

Analysis

As a first step, basic descriptive statistics, frequency counts, and bivariate correlations were computed for all relevant variables. Then

analyses of variance (ANOVAs) were performed to test for differences in mean scores on each of the six scales based on age, educational level, income level, recurrent versus nonrecurrent cancer, length of survival (5–10 years vs. longer), cancer site (breast, uterine, colorectal, ovarian, lung, lymphoma, or other), and location of residence (urban, suburban, or rural). When testing for differences according to survival time, we made age a covariate. For the ANOVAs, the women were grouped according to age (under 40, 40–49, 50–59, 60–69, 70–79, or 80 or older) and income level (less than \$20,000, \$20,000–\$39,999, \$40,000–\$59,999, or \$60,000 or higher).

RESULTS

The women's mean scores on the six scales are presented in Table 1. Their most positive scores were in the psychological and sexual areas, and their least positive score was in the area of social/emotional support giving.

The results of the correlation analysis are presented in Table 2. The women's psychological states proved to be highly correlated with their somatic concerns and sexual satisfaction. On the other hand, somatic concerns were highly correlated with sexual satisfaction and, to a less degree, with health habits. Women who had a positive philosophical/spiritual outlook were more likely to have good health habits and be supportive of others.

The ANOVAs revealed that both better educated women and those with higher incomes were more willing to give support to others (Table 3). Women in midlife tended to have a more positive philosophical/spiritual outlook and were more willing to give support than were either the youngest (under 40) or oldest (80 or older) women. Those who had suffered a recurrence of their cancer generally reported higher levels of

Table 1. Total sample's ($N = 191$) mean scores, standard deviations, and reliability coefficients for all scales

| Scale | M^a | SD | p |
|---------------------------------|-------|------|------|
| Somatic concerns | 1.17 | 0.69 | 0.85 |
| Philosophical/spiritual view | 1.54 | 0.84 | 0.89 |
| Health habits | 1.90 | 0.91 | 0.89 |
| Social/emotional support giving | 2.46 | 0.98 | 0.87 |
| Psychological state | 0.81 | 0.88 | 0.93 |
| Sexual satisfaction | 0.99 | 1.20 | 0.88 |

^aThe range for each scale was 0–4.

Table 2. Bivariate correlations among the scales ($N = 191$)

| Scale | Somatic concerns | Health habits | Psychological state | Philosophical/spiritual view | Social/emotional support giving |
|---------------------------------|------------------|---------------|---------------------|------------------------------|---------------------------------|
| Health habits | .231** | | | | |
| Psychological state | .686*** | .104 | | | |
| Philosophical/spiritual view | -.056 | .471*** | .021 | | |
| Social/emotional support giving | -.137 | .278*** | -.140 | .384*** | |
| Sexual satisfaction | .492*** | .175* | .533*** | -.029 | -.076 |

* $p < .05$.** $p < .01$.*** $p < .001$.

somatic concerns and were more willing to give support to others. Their psychological states were also worse than those of women who had not suffered recurrence, although the difference was not statistically significant. Women who had survived 5–10 years on average reported fewer somatic concerns and greater sexual satisfaction, and those who had survived longer than 10 years were more eager to be of support to others experiencing cancer. Women who had experienced breast cancer reported the highest levels of somatic concerns, and women who had suffered colorectal or ovarian cancer were the least likely to be supportive of others. There was no statistically significant variation in either health habits or psychological state for any of the factors. Location of residence was not a statistically significant variable for any of the areas surveyed.

DISCUSSION

This sample of long-term cancer survivors tended to be older (average age = 60.6 years) and reported considerably more positive scores for the psychological, sexual, and somatic areas than for the remaining areas. At this point in their lives, these women clearly did not perceive themselves to have many concerns in these three important areas of quality of life. This is consistent with Vinokur et al.'s (1989) finding that breast cancer patients who survived up to 5 years reported levels of psychosocial adjustment similar to those reported by a control group of asymptomatic women. Our sample's mean sexual satisfaction score, being the second

Table 3. Results of analysis of variance for effects of variables on scores on all scales ($N = 191$)

| Variable | Somatic concerns | | Health habits | | Psychological state | | Sexual satisfaction | | Philosophical/spiritual view | | Social/emotional support giving | |
|---------------------------------|------------------|------|---------------|------|---------------------|------|---------------------|------|------------------------------|------|---------------------------------|------|
| | F | p | F | p | F | p | F | p | F | p | F | p |
| Age | *1.444 | .211 | .880 | .496 | .337 | .890 | .929 | .464 | 2.660 | .024 | 3.943 | .002 |
| Educational level | .635 | .638 | 2.160 | .075 | .461 | .764 | .577 | .680 | .976 | .422 | 2.445 | .048 |
| Income level | 1.690 | .172 | .932 | .427 | .853 | .468 | .500 | .683 | 1.077 | .361 | 4.782 | .003 |
| Recurrence status | 24.980 | .000 | .799 | .373 | 3.642 | .058 | .760 | .385 | .044 | .834 | 6.451 | .012 |
| Length of survival ^a | 8.727 | .004 | 1.047 | .265 | 3.788 | .054 | 4.496 | .036 | .231 | .632 | 5.013 | .026 |
| Cancer site | 3.808 | .001 | 1.623 | .143 | 1.324 | .250 | .239 | .963 | .912 | .487 | 3.045 | .007 |
| Location of residence | .164 | .849 | .468 | .627 | .245 | .783 | .190 | .827 | 1.105 | .334 | 2.102 | .125 |

^aAge was used as a covariate in the analysis of the effects of length of survival.

best of their adjustment scores, suggests that these women had few concerns regarding this aspect of their lives. Kaplan (1992) noted that all current treatments for breast cancer can have serious sexual side effects and that this important aspect of cancer care has been largely neglected by medical and mental health professionals. If the women in our sample experienced sexual problems or concerns related to their cancer or its treatment, they appear to have resolved them.

The most striking results of the correlation analyses were the substantial correlations among the somatic, psychological, and sexual areas. These findings were not surprising—intuition suggests that somatic well-being plays a role in both psychological and sexual well-being.

The greater willingness of women with higher levels of education and income to provide social and emotional support to other cancer patients could perhaps be explained in part by their feeling more confident in their communication skills and having greater resources at their disposal than those with less education and income.

Understandably, women who had experienced a recurrence of their cancer reported more somatic concerns than those who had not had a recurrence, and they indicated a greater willingness to give support to others. Having faced both the initial diagnosis and treatment and the additional trauma of recurrence, these women were indeed in a position to understand the physical and emotional trauma experienced by other cancer patients. Perhaps this deeper knowledge of the cancer experience and their resilience in dealing with it account for their greater desire to help other cancer patients.

The finding that the women who had experienced breast cancer had the highest levels of somatic concerns could perhaps be explained by the physical debilitation that results from mastectomy. Of the 110 breast cancer patients in the sample, 88 (80%) had undergone a mastectomy as part of their treatment.

Although age was not a very important variable, women in midlife reported a better philosophical/spiritual view and indicated a greater desire to be of support to other cancer patients than did women in the oldest and youngest age groups. On the other hand, length of survival had a significant effect on three of the six areas of adjustment surveyed: somatic concerns, sexual satisfaction, and support giving. The greater desire of longer term survivors (more than 10 years) to be of support to other cancer patients could perhaps be explained by their longer experience in having survived cancer and their empathy for others struggling with this illness. The finding that those who had survived longer than 10 years reported more somatic concerns than did those who had survived 5–10 years may be related to the influence of age and other comorbid conditions. However, why the women who were longer term survivors

reported lower levels of sexual satisfaction is puzzling. We conjecture that because 80% of the breast cancer patients in our sample had had mastectomies, the associated disfigurement may have caused a decrease in sexual interest on the part of these women's partners. It is important to see whether these results are replicated in other samples of long-term cancer survivors.

One of the most interesting findings of the present study was the desire or willingness of the women to be of support to other patients with cancer. Although the total sample's mean score on this scale was not very good, selected groups reported significantly better scores. It is critical for health care professionals to be able to identify those cancer survivors who might be willing or even eager to lend support to other cancer patients, either individually or in the context of support groups.

In summary, the women in this study reported generally good psychological states and relative satisfaction with their sexual lives. However, women who had experienced recurrence of their cancer, were longer term survivors, or suffered from breast cancer all reported higher levels of somatic concerns. Physicians and nurses who provide care to women who have survived cancer for longer periods must be cognizant of the potential for ongoing somatic concerns. They should reinforce the importance of good health habits and psychological well-being and provide opportunities for interested long-term survivors of cancer to be of support to women newly diagnosed with cancer.

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Breast cancer survivors: An exploration of quality of life issues

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This article explores long-term survivorship (5 years or longer) through focus group discussions with women who have experienced breast cancer. The data revealed four major themes; integration of the disease process into current life, change in perspective, and unresolved issues. These data begin to shed light on the issues of breast cancer survivors and can provide a basis for development of a quantitative instrument to be tested with larger populations

Key Words: Quality of life—Breast Cancer—Focus groups—Survivorship.

Breast cancer will be the most commonly diagnosed cancer in 1993, with ~182,000 new cases expected (1). These figure means that one of every eight women in the United States will develop breast cancer during her lifetime; however, 85% with early-stage disease will survive ≥ 5 years. The

American Cancer Society estimates the 5-year survival rate for women diagnosed with breast cancer as follows: 100% with in situ breast cancer, 93% with localized breast cancer, 71% with regional spread, and 18% with distant metastases (1). This increasing number of women surviving breast cancer points to the need to explore the quality of life among these women.

Mullan (2), the founder of the National Coalition for Cancer Survivors, conceptualized survivorship into three categories: acute, extended, and permanent. Acute survival is dominated by treatment, i.e., medical, surgical, and radiologic. Extended survival is characterized by remission or termination of the basic and rigorous course of treatment. This is a period of "watchful waiting" with periodic examinations and intermittent therapy. Permanent survival is the evolution from the extended phase into a period where activity of the disease or likelihood of its return is sufficiently small that the cancer is considered to be arrested.

An extensive body of research exists to cover the first two phases outlined by Mullan (2); however, investigators have only begun to identify the issues of long-term, permanent survival. In light of this deficit in the literature, a qualitative study was designed to identify quality of life issues for women who have survived breast cancer for ≥ 5 years. The intent was to better understand this vast and growing population of long-term survivors from their perspec-

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tive and to isolate themes to serve as a basis for a future quantitative study.

LITERATURE REVIEW

Because many women with breast cancer live well beyond their diagnosis and treatment for the disease, it is nursing's role to examine their issues from a holistic perspective and understand who these women are or who they become as they integrate their experiences of cancer into the rest of their lives. This aspect, which goes beyond the medical diagnosis and treatment, is referred to in the literature as psychosocial adjustment or psychooncology, but more commonly it is referred to as quality of life.

The one major study that followed women for 5 years was conducted by Vinokur et al. (3). The variables measured were both psychosocial and physical (3). One hundred sixty-two women with breast cancer were matched with 162 asymptomatic women from the same screening clinic. Measures covered three areas: demographics, breast cancer disease, and adjustment outcomes. Quality of life was measured on a seven-point scale covering 14 major life domains (3,4). Results indicated that women with breast cancer manifested nearly the same level of quality of life as asymptomatic women in the same screening population. This overall finding was consistent with an earlier study involving 5-year postmastectomy patient adjustment (5).

Nevertheless, when specific subsets within the Vinokur et al. study (3) were reviewed, several interesting findings emerged. The analysis of age found that older women (>64 years) coped better with the stress of cancer than did younger women; however, another study suggested that age was not significantly related to postmastectomy distress (6). Vinokur et al. (3) also found that the more recent and severe cases of breast cancer produced serious difficulties in psychological adjustment for younger and middle-aged patients (<64 years), and particularly serious medical problems and physical difficulties in adjustment for older patients. Vinokur et al. (3) acknowledged limitations to their study in the following ways: (a) 70% of their subjects had very early stage disease with no nodal involvement; (b) the educational and economic level of their subjects far exceeded the general population; and (c) although their population represented the state of Michigan, the subjects were primarily from southeastern (suburban) Michigan where the clinic was located.

In another project Woods and Earp (7) studied 49 breast cancer subjects at 4 years postmastectomy. Their sample, which included younger women who presented with early-stage disease, was not generalizable due to the limited number of subjects. They found that social support was a psychological buffer to an extent; however, there was a physical distress threshold beyond which this buffer was ineffective (8).

Survivorship research for breast cancer has received mixed reviews. There has been criticism concerning methodology, conceptualization, and the narrow field of interest investigated (9). Many studies have focused on one specific aspect of psychosocial adjustment, such as social support (10,11), significant other (12), return to work (13,14), sexuality (15), conservation versus mastectomy surgery (16,17), and aerobic exercise (18).

A compilation of studies reported by Irvine et al. (9) reviewed breast cancer studies from 1972 through 1989 in which multiple variables were tested to determine psychosocial adjustment. The instruments used ranged from well-established psychiatric tools (such as the Minnesota Multiphasic Personality Inventory and Rorschach ink blot test) to untested author-constructed questionnaires and interviews. Although many of these studies were longitudinal, the longest period that subjects were followed on any study was 22 months. The research appeared especially heavy at intervals covering the first year since diagnosis and then began to drop off during the second year. According to Ell et al. (19), numerous studies found psychosocial factors to be associated with psychological adaptation, but few studies examined the potential influence of psychosocial factors on response to breast cancer over time.

Padilla et al. (20) integrated many of the previously identified variables of quality of life into a conceptual model. In their study defining the content domain of quality of life for cancer patients with pain, Padilla et al. (20) derived three categories of attributes embracing quality of life: (a) physical well-being, (b) psychological well-being, and (c) interpersonal well-being. During the 1980s an attempt was made to develop instruments specific to cancer for measuring quality of life variables (21-24). Ciampi et al. (21) measured quality of life using four variables: social, physical, emotional health, and disease-related issues. McCaughan et al. (22) defined quality of life as encompassing five major life areas: functional ability, social interaction, comfort, health, and economics. Coates et al. (23) used a quality of life index

that included physical well-being, mood, pain, and appetite. However, none of these instruments have been tested with long-term survivors of breast cancer (≥ 5 years), nor do they incorporate a holistic approach covering all four domains (physical, social, psychological, and spiritual).

To respond to this deficit in the literature, a study was designed to investigate the quality of life of long-term breast cancer survivors through a holistic framework. The Ferrell model (25,26), which elaborated on the Padilla et al. (20) framework to include spirituality, was specifically designed for cancer survivors. The Ferrell framework was applied to this study because it included all domains relevant to quality of life, i.e., physical, social, psychological, and spiritual. Ferrell's physical domain encompassed areas such as symptoms associated with surgery and combination therapy. The psychological domain covered concerns such as fear of recurrence, anxiety, depression, and body image. Social concerns covered altered roles and relationships, issues regarding family, and a sense of isolation. Spiritual well-being addressed the meaning of illness, degree of religiosity, and heightened awareness of death (25).

METHOD

Design

The study design was qualitative, using focus group discussions. The discussions addressed quality of life issues, concerns, and needs experienced women who had survived breast cancer for ≥ 5 years. To set the stage for the discussion, the women were asked to reflect on the time period beginning at their 5-year anniversary since diagnosis and proceeding to the present. Based on the Ferrell domains of quality of life, broad, open-ended focus group questions were posed. In addition, a subset of more specific questions from each of the four domains were also prepared to facilitate discussion. The four major probes were as follows:

1. Physical—How has your body adjusted/responded over this time period to your experience with breast cancer, the treatment, and rehabilitation process?
2. Social—How has your social life-style been affected as a long-term cancer survivor? This could include thoughts on family relationships, friendships, employment, community activities, vacations, support groups, or any other social situations that come to mind.
3. Psychological—What emotional adjustments have you made as a long-term breast cancer survivor?
4. Spiritual—What shifts have you been aware of in your spiritual beliefs, feelings, or practices? We realize that many people have nonreligious modes of expressing and experiencing their spiritual feelings, so please do not feel limited to religious responses unless that is right for you.

Sample

An invitation to participate in the focus group discussions was mailed to a convenience sample of 38 long-term breast cancer survivors residing in Michigan, as identified through their clinic records (diagnosis in 1987 or earlier). Of the 38 women identified, 21 responded to the invitation. Of the 21 who responded, 11 consented to participate in the focus groups. A high percentage of potential subjects responded but were out of state in a warmer climate during winter data-collection months. These self-selection factors introduce a possible bias to the sample.

The sample was composed of women who had survived breast cancer for 5–14 years (mean = 10). All participants met the following criteria: (a) surviving breast cancer a minimum of 5 years since their initial diagnosis, (b) willing to participate in focus groups, (c) understanding and speaking English, and (d) not having a diagnosed mental illness. The ages of the women ranged from 40 to 79 years (mean 61). The women were divided into two groups, morning and evening, according to their availability. The morning group consisted of five participants, and the evening group consisted of six participants.

Twenty-seven percent of the women were employed (18.2% part time and 9.1% full time). Generally the participants in the morning group worked outside the home and did some volunteer work, whereas participants in the evening group were not employed outside the home, although several did volunteer work in the community. Five of the participants were married, three were widowed, two were divorced, and one had never married.

All of the participants had had a mastectomy. One participant who had one recurrence of breast cancer also had undergone a lumpectomy on the opposite breast. Adjuvant therapy varied, with one woman receiving only tamoxifen, seven receiving chemotherapy, two receiving chemotherapy and tamoxifen, and one receiving no adjuvant therapy.

Procedure

Two sets of focus groups met for two sessions that each lasted 2½ h. The investigators cofacilitated all sessions. One of the investigators was a clinical nurse specialist who had worked with oncology patients for the preceding 12 years and had facilitated numerous groups. The other investigator was a psychotherapist who had counseled women on grief and loss and had presented seminars to physicians on cancer disclosure to patients and families. Besides the two researchers who facilitated the discussions, two nursing research assistants greeted the participants as they arrived and offered them coffee and cookies; the assistants took notes and managed the tape recordings of the sessions. The researchers began with group-forming activities, which included reviewing the informed consent that had been sent with the mailed invitation, offering self-introductions, then asking the women to do the same.

Questions from the physical domain were the initial topic for the first session. From past experiences with groups, the investigators thought that the women would be least inhibited beginning with this area in a newly formed focus group. The second area of questioning during session 1 was on the social domain, because the women were comfortable talking about their friends, family, and social supports. The second session then focused on the more personal domains, i.e., psychological adjustment and needs, and spirituality, which is generally the most intangible and often difficult to assess or describe.

Analysis

Immediately after the sessions, the investigators individually recorded observational notes, including preliminary themes that emerged during the group discussions. The investigators then met to discuss these preliminary themes before the second sessions. The tape recordings of the groups were transcribed verbatim by the two research assistants and reviewed for accuracy by the researchers. A graduate nursing student experienced in qualitative methods was the fifth member of the research team; she was not present during the sessions. One of her roles was verifying the accuracy of transcriptions by listening to the tapes while following along with the typed transcriptions.

Because focus group questions had been derived from the holistic framework of Ferrell (25), responses to the questions were analyzed within this context, i.e., physical, social, psychological, and spiritual. The conceptual framework was used to create a scaffolding

for the categories derived from the focus group questions.

Data were managed using the Ethnograph computer program. The coinvestigators initially worked independently with both transcriptions and session notes to begin uncovering potential codes. In developing the codes, frequency of response was taken into consideration. These independently derived codes were compared, and coding categories were settled upon as agreement was reached. Coding categories were then verified by two other members of the research team (the graduate assistant with qualitative experience and one of the two nursing research assistants on the project) by extracting transcription sections that they coded independently. The entire research team then met to reach agreement on an inclusive list of 14 coding categories within the Ferrell framework.

Seven coding categories emerged under the physical domain: (a) eating habits, (b) body image, (c) prosthesis, (d) apparel, (e) pain, (f) exercise, and (g) change in senses. Three categories evolved from the social domain: (a) change in social support, (b) desire to be of service to others, and (c) relationships with health-care providers. The psychological domain produced two categories: (a) susceptibility to cancer and (b) change in perception of health/illness. The spiritual domain also brought out two categories: (a) spiritual guidance for health decisions and (b) change in philosophical view of life.

The research team was then reconstituted to include the primary investigator, the graduate nursing student with experience in qualitative research, and one of the two research assistants who had attended the sessions. This research team independently coded the transcripts according to the derived categories and subsequently came together to reconcile coding discrepancies.

Following procedures suggested by Krueger (27), themes were identified from the coding categories. This often meant returning to samples of actual quotes to explain rationale for potential themes. Using an open verbal format, the team was able to hear and take notes on the eventual consolidation of themes. Initially the team isolated eight themes. At this point, a concurrent emphasis was placed on developing questions/items for a future quantitative instrument, which helped to further consolidate categories into key themes. In the end, this process allowed the research team to capture four major themes related to quality of life for this sample of breast cancer survivors: (a) integration of the disease

process into current life, (b) change in relationship with others, (c) restructuring of life perspective, and (d) unresolved issues.

Once the four themes were identified, team members independently organized the coded data under each theme. The team then reconvened to reach agreement on placement of all coded data within the four major themes. Specific comments were taken from the computerized data base to illustrate each theme. Through this process the research team was able to synthesize the complexities of life expressed by survivors of breast cancer through the crossover of domains and influence of one domain on the others.

RESULTS

Themes

Two of the four themes included categories from more than one of the conceptual framework domains (physical, social, psychological, and spiritual well-being), whereas the other two themes dealt solely with categories from the physical or social domain.

Theme 1: Integration of the Disease Process into Current Life

This theme was composed of data coded into the categories of body image, eating habits, exercise, pain, changes in senses, prosthesis/reconstruction, and change in apparel. These categories all came from the physical domain and represented areas in which the women felt that although they had to make adjustments, the adjustments were tolerable. They could recall a period of loss or change that initially created concern and stress, but at this time they felt they had coped with the adjustment and did not continue to struggle with the loss or change. Comments on this theme centered around a change in body image due to loss of a breast and associated physical changes and habit patterns. Examples of the integration of these changes into current life are as follows:

I needed my breast when I raised my six children, but that was then. I don't need it now, so I don't worry about it.

I feel normal now. If I were to wake up tomorrow with another breast, I would look funny.

Other adjustments were raised as follows:

A lot of women have problems, depending on how much it [prosthesis] causes them to sweat. They are heavy, too, but I'm thrilled to have it; I don't care.

The adjustments to pain and change in senses took place over a longer period of time.

I had a lot of residual pain in my elbow after my mastectomy, and I'm sure others did, too. I think some nerves were cut or something; I had a lot of weird sensations. I couldn't tolerate a necklace going over to the side for quite some time.

I have always had swelling since my mastectomy and some numbness. I had to have all my rings made bigger and never wear sleeveless dresses that would show the swelling.

Theme 2: Change in Relationship With Others

Coding categories for this theme came from the social and psychological domains of the conceptual framework and included change in perception of health/illness and changes in social support. Comments supporting this theme included a decreased toleration of minor complaints from others:

In situations of loss or death I am real compassionate, but for whining, I have no tolerance, and I will confront someone now who is whining.

Another subject, who was a nurse, expressed her feeling in the following way:

That is why I quit my previous job, because I got tired of all the colds that wanted to be better yesterday. I have trouble showing compassion for people who are complaining about little things that in a week will be gone.

Another recurring comment within this theme was change in patterns with friends and relationships with family members. Many of the participants indicated they had become closer with family members; others indicated that some friends avoided them since they were diagnosed with cancer:

My daughter was deeply affected by my cancer. She still sends me [an] anniversary card every year, like "six down, four to go" and this type of thing. So they [my children] still remember it.

I still think of one or two friends that my friendship have changed, and I haven't been able to rebuild that friendship, because of their fear of mortality.

Some of my newer friends know I have had cancer and some don't. I decide if I think they can deal with it, whether I tell them or not. I was on a TV news interview about cancer. Some of the ladies at work said they saw me, and I did a really good job. I could tell that some people saw it and couldn't say anything; it was a different look and it's not something I watch

for, but you develop a sense for the people who have a hard time talking about cancer.

The biggest problem I have had is with my mother. She likes to be the center of attention and my cancer has taken that away from her. I am learning not to let her bother me so much.

Clearly, there was great variety expressed in how relationships had changed. There seemed a keen awareness among these women of what their cancer experience had meant to them and how it had affected those closest to them.

Theme 3: Restructuring of Life Perspective

Theme 3 included information from three domains (social, psychological, and spiritual) and consisted of the following categories: change in philosophical view of life, desire to be of service to others, change in perception of health/illness, and spiritual guidance for health decisions. Many participants indicated they were living more in the here and now. This perception included comments about giving new meaning to simple experiences, not taking life for granted, and having greater appreciation for the small things in life and greater attention/thankfulness for time.

I don't take life for granted. I don't take any of my family members for granted. I'm on borrowed time, so I take advantage of it.

There were also examples of a desire to be a resource to others:

I am a resource person for people from my church, and I have a lot of people come to me to talk with their mother or sister.

Further support for this theme came from the spiritual domain. The women described experiences that were a help and comfort to them, but that went beyond the explainable:

I had a real close grandmother-type friend who died a week before my diagnosis of breast cancer. I found my lump by accident. I think she was still trying to help me after her death, and my love for her made it possible.

When my husband and I were trying to decide about my surgery, we heard "our" song on the radio from when we were sweethearts. We felt that was a sign that everything was going to be all right, a sign from God.

I was going to the doctor about my diagnosis. I had a vague idea where the office was, but it was so traumatic; I didn't know if I could go through it [cancer treatment]. I pulled out into the street and there was a little red

sports car driven by a little old lady with white hair. She smiled at me and I started following her. She proceeded to turn on every street in the direction I needed to go 'til I got to the office. This may not sound like a big deal, but it was the spiritual support I needed that day. I never saw her again.

Theme 4: Unresolved Issues

The final theme included coding categories from the social and psychological domains related to patients' relationships with health-care providers and fears of susceptibility to cancer. For example, one participant stated the following:

I get the feeling they don't check carefully enough, the doctor is not thorough. The checkup is very casual. He doesn't take my concerns seriously.

Several women felt they were not included actively in their health-care planning. This was expressed by anxiety over delays in test results. They would have preferred immediate feedback once tests were completed. One woman had even worked out codes with the technician to get this information in a timely fashion.

When my bone scan looks good, the technician says, "nice day today."

Several women also felt susceptible to recurrence.

I have less frequent checkups now, and sometimes I dread them. Maybe this time span will let something start and I won't be right on top of it.

I still don't renew subscriptions for three years, just annually.

DISCUSSION

This study offers a message of hope for patients, families, and health-care providers. Women do survive breast cancer and with many positive outcomes. One of the clearest findings is that people do not fit their lives into domains. Instead, concerns/issues often cross over into two or more domains of life: physical, social, psychological, or spiritual. This implies that quality of life is a dynamic concept, with great diffusion across domains. These women exemplified the holistic philosophy underlying nursing practice.

Secondly, it appears nearly impossible for breast cancer survivors to begin at the 5-year survival point to tell their story. It is like a story without a beginning, and who they are today has its roots in the experience they had at the time of diagnosis. This seems especially clear in the spiritual domain. The women all had

changed and strengthened spiritual views, but this was due to an experience that had truly moved them at that most vulnerable time of diagnosis and early treatment. These experiences continued to lend support to their lives at the present time.

Integration of the Disease Process into Current Life

In the physical area the women had been, and continued to be, information seekers and problem solvers in dealing with issues/concerns, i.e., the heaviness of their prostheses and the sweating they caused, the changes in sensations they experienced, changes they made in clothing and jewelry, and changes in health-related habits (eating and exercise). They incorporated these physical adjustments into their individual lives over time. Rather than each woman searching for resources on her own with varying degrees of success, nurses could provide support and guidance for issues at a much earlier point.

Change in Relationship with Others

Theme two pointed out changes in relationships with friends, family and others. Moreover, these women's perceptions of health and illness were affected, producing a more assertive attitude toward others regarding severity of illness. Early intervention could help women prepare for these changes and anticipate them. Although support groups abound for newly diagnosed breast cancer patients, support groups for long-term survivors could be designed to include the issues brought forth by this theme. Indeed, ongoing nursing interventions for the long-term survivors should include continued coping with changes in friend and family relationships.

Restructuring of Life Perspective

The third theme demonstrated dramatic shifts in life perspective. Across the groups, one of the most outstanding features was the women's desire to be of service to others. Almost all volunteered in their community, especially in the area of breast cancer information. This was an area where they believed they had something to offer to others. To be of service added meaning to their lives through sharing with others who were newly diagnosed or seeking information. It was a message of hope not only for the newly diagnosed, but a renewal of hope for themselves. To capitalize on their desire to be of service, long-term survivors should be encouraged to facilitate support groups or speak for community organizations. Such activities might prove to be rewarding to many long-term survivors and serve as a

type of catharsis by reliving some of their experiences as a survivor of cancer.

Another shift in life perspective was spiritual in nature. This is an often neglected or minimized area in nursing assessment and intervention. Every woman in the study had a spiritual experience to relate, something that went beyond what they could readily explain. They were delighted to finally be asked about this aspect of their lives and to be encouraged to discuss it in a receptive environment. This is an area warranting further nursing attention at multiple points in the survival process. Nurses could initiate these discussions and provide support through the women's belief system, thus adding to their quality of life.

The theme of change was capstoned by the new value subjects had learned to place on life for each day, each experience, and each person they knew or met. The cancer experience had taught them to "stop and smell the flowers." The women had also gained a much broader definition of what health and illness were. All said it would be impossible for them to go back to their old way of thinking, that a cold or flu mattered. They recalled getting concerned about these things but now knew how to keep such thoughts in perspective.

Unresolved Issues

Theme 4 represented the areas that the women had not yet reconciled. Nursing should consider these issues. How can we facilitate earlier feedback on diagnostic tests and follow-up studies and involve women in their own health care? Interventions for long-term survivors of breast cancer should also include information on knowledge of the disease and state-of-the-art diagnostic and treatment procedures. The women in this study demonstrated that they were truly information seekers, eager to become active participants in their own health care.

Knowledge is power, and knowledge regarding test results and probabilities of recurrence can help reduce fears of susceptibility to recurrence or to new cancers. Nurses can serve a vital role in providing this information to breast cancer survivors, thus perhaps reducing these anxieties. Moreover, nurses should become greater patient advocates in facilitating timely reporting of test results.

Finally, the long-term survivor may benefit in multiple ways from support groups specifically geared to the needs of the long-term survivor. Support groups may help women realize they are not alone with their concerns and can help each other deal with unresolved issues. They can provide advocacy by

encouraging assertive behavior (e.g., requesting earlier reporting of follow-up tests) and empathic problem solving for social and physical issues specific to this group.

Limitations

This was a small self-selected population. Qualitative research such as this cannot be generalized to any larger population; rather, it can only suggest trends. These trends can later be tested for generalization through larger quantitative research projects.

Strengths

The sequencing of questions worked well because the women were comfortable with each other by the second meeting and willing to talk about more personal or private issues of emotions and spiritual topics. Descriptive qualitative methodology was used, appropriate when a paucity exists in an area. The open-ended questions sought nonsuggestive responses directly from participants. There was peer support to share and elaborate on ideas/issues using the focus group format. Focus groups have been a natural format in various clinical settings when the need has been to elicit concerns in a nonthreatening, supportive environment.

Finally, the categories and themes that emerged proved useful for the development of a quantitative questionnaire designed for long-term survivors. Through focus group discussions this study has uncovered variables not tapped by instruments currently available. These variables have the potential of making a critical addition to the science of long-term quality of life for the many women who are surviving breast cancer.

Recommendations

This study needs to be replicated, including women from broader demographic backgrounds, minorities, and rural areas to enhance the findings. Also, groups of female survivors of other types of cancers could be studied to assess similarities of needs. Because there is only one study in the literature of women followed longitudinally for 5 years from diagnosis, replication with more nursing focus would identify issues emerging at various points in survival. This approach would allow for a trajectory of survival to be developed.

Finally, a qualitative study such as this can serve as a foundation for a quantitative approach to assessment. Once needs are identified, nursing interventions can be tailored to focus on key issues and times of

stress for the long-term cancer survivors. The next step is to assess a larger population of long-term survivors using quantitative measures.

CONCLUSION

According to Hassey-Dow (28), "The process of survival is gradual and often undramatic. Those who thrive after cancer have gained a perspective on life and death, often discovered a new or reborn faith, choose battles carefully and are not afraid of risk." Nurses are presented with a challenge to find new ways to enhance long-term survival. □

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A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

LIMITED DISTRIBUTION MATERIALS

(Submitted Abstract and Manuscripts)

Appendix D

Abstract

Wyatt, G. (Submitted August 15, 1997). Bridging the gap between nursing outcomes and the research process: One-step computerized documentation and direct data entry. Abstracts submitted to the Oncology Nursing Society for conference to be held May 7-10, 1998 in San Francisco, California.

Manuscripts

Wyatt, G., Ogle, K., & Given, B.A. (Submitted August, 1997). Improving access to hospice care: A perspective from the bereaved. Journal of Palliative Care.

Wyatt, G. & Friedman, L. (Re-submitted September, 1997). Physical and psychosocial outcomes of midlife and older women following surgery and adjuvant therapy for breast cancer. Submitted to Oncology Nursing Forum.

BRIDGING THE GAP BETWEEN NURSING OUTCOMES AND THE RESEARCH PROCESS: ONE-STEP COMPUTERIZED DOCUMENTATION AND DIRECT DATA ENTRY. Gwen K. Wyatt, RN, PhD, College of Nursing, Michigan State University, East Lansing, MI 48824-1317.

Computers and software are now an essential aspect of research. Data analysis is the established association that researchers have with computers. However, as computers become more a part of everyday life and software improves, computers are being included in many aspects of the research process. The purpose of this paper is to share our computerized documentation system for nursing care, using preliminary data from our four year "Nursing Care for Breast Cancer Study," funded by the Department of Defense #DAMD17-96-1-6325. Over the four years of the study, 200+ women who have had short-stay (48 hours or less) breast cancer surgery will be enrolled in a randomized clinical trial. Women in the intervention arm receive nursing care in their home and phone contacts during the first two weeks following surgery. The computerized patient documentation program also serves as the research data entry program. Nurses omit the traditional step of creating a paper chart. Within the software program, study nurses can chart data on physical assessment, symptom experience, incision self-care, drain management, teaching/learning on BSE, lymphedema prevention, ROM of the affected arm, and nursing diagnosis and interventions. This program further allows data analysis and summary at any time to assess factors, such as the most commonly used nursing diagnosis and interventions, which establishes a direct linkage between the nursing process and intervention outcomes. Along with the clear advantages of combining steps in the overall research process, there are also challenges in terms of the "learning curve" for nurses who have varying degrees of computer literacy and are accustomed to paper charts. It is expected that the trend toward increased use of computers in research will ultimately streamline the overall process, but several implementation issues will need to be addressed as well.

MICHIGAN STATE UNIVERSITY

COLLEGE OF NURSING

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August 27, 1997

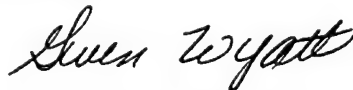
Dr. David Roy, Editor-in-Chief
Journal of Palliative Care
c/o Center for Bioethics
Clinical Research Institute of Montreal
110 Pine Avenue West
Montreal, QC
Canada H2W 1R7

Dear Dr. Roy:

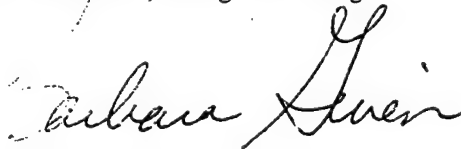
We wish to submit our enclosed manuscript for your review for potential publication in the "Journal of Palliative Care". It is entitled, "Improving access to hospice care: A perspective from the bereaved". Dr. Wyatt will serve as the major corresponding author. Each of the authors have verified the references and bear responsibility for the accuracy of the references cited.

We look forward to your reply.


Sincerely,



Gwen K. Wyatt, R.N., Ph.D.
Associate Professor, College of Nursing



Barbara A. Given, Ph.D., R.N., F.A.A.N.
Professor, College of Nursing



Karen S. Ogle, M.D.
Professor, Department of Family Practice

**MICHIGAN STATE
UNIVERSITY**

March 15, 1996

TO: Barbara A. Given
A230 Life Sciences

RE: IRB#: 94-116
TITLE: A SURVEY OF ATTITUDES ABOUT HOSPICE CARE
REVISION REQUESTED: N/A
CATEGORY: 1-C
APPROVAL DATE: 03/15/96

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project and any revisions listed above.

RENEWAL: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.



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CHANGES:**

Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

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Improving Access to Hospice Care: A Perspective from the Bereaved

To be submitted to:
Journal of Palliative Care

by:

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The Office of the Vice Provost for Outreach
Michigan State University, East Lansing, Michigan

Abstract

Access to hospice care continues to be an enigma. Hospice have been available for the past two decades in the United States, but the services continue to be underutilized. In an effort to better understand access barriers, a series of focus groups were held with recently bereaved (mean 9.9 months) caregivers. During the process of the focus group discussions, participants relived and relayed to each other their entire hospice experience. While the purpose of this research was to uncover access issues, participants actually integrated their access comments into the overall richness of their hospice experience. The twelve participants were divided into two groups, and each group met twice during June, 1996. From the focus group discussions, six general hospice themes emerged. In addition, six major areas of recommendations to improve access to hospice were generated: public issues, family caregiver areas, professional education topics, health professional issues, agency ideas, and community comments.

Improving Access to Hospice Care:

A Perspective From the Bereaved

Since the concept of hospice was first brought to public attention in 1967 by St. Christopher's hospice in England, there has been worldwide support for the movement (Lair, 1996). Care with a focus on comfort and the total person has made the final period of life more emotionally and physically comfortable for many patients and their families. However, many continue to go without hospice care during the terminal phase of life. Reasons such as cost and quality of care are often used to justify the dismissal of hospice as a personal method of terminal care (Mor, 1988). Most people hold to the silent hope that they will never need hospice services.

The majority of patients in hospice care are cancer patients, yet only one out of every three people who die from cancer are enrolled in hospice. Further, only 14.7% of all deaths in the United States from all causes are tended to by a hospice program (National Hospice Organization, 1996). Often, the acceptance of hospice support is seen by the patient and family as the last step in a health crisis, and for many, this signifies a letting go of hope. For this and many other reasons, access to hospice care has received little attention to date. Hospice service was assumed available to the general public, and merely needed to be requested. However, the majority of patients and family caregiver dyads who qualify for hospice care do not receive care, or receive only limited days or weeks of support--far less than the six months that is available (National Hospice Organization, 1996).

Literature Review

Much anecdotal literature has focused on the lack of early referral, and posit both negative attitudes and a lack of knowledge by physicians as the primary causes for late referral (Jones,

1996; Appleton, 1996). To date, the professional literature on hospice related to patients and families has taken two focuses. One focus has been on the period of dying, emphasizing the concerns and conflicts associated with that period. The second focus has been upon the intrapsychic issues of the dying person (Lair, 1996). Very little attention has been placed upon initial access to hospice care, with the few exceptions of issues surrounding hospice access for minority groups (Gordon, 1995; Harper, 1995).

Access to hospice is often hindered by a lack of knowledge on the part of the health provider related to how hospice regulations function and the goals and benefits of care. Poor patient education regarding hospice, and professional disagreement over admission criteria limit hospice access to very specific disease conditions and tie the physician's hand regarding prognostication. Some physicians believe that by not treating every patient aggressively, they are abdicating their responsibility as a medical professional. Physicians continue to avoid discussing death with their patients when it might be reasonable to discontinue aggressive treatment, due in part to the fact that patients are sometimes unwilling to accept the fact that their disease is incurable (Jones, 1996). In an editorial, Lo (1995) raises many questions regarding end of life care. He stresses that more attention needs to be placed upon: (a) discussions between physicians and patients; (b) physician's and patient's estimate of prognosis; (c) respect for patient's informed refusal of interventions; (d) and physicians appreciation of patient's pain. Finally, some hospice agencies require a primary caregiver in the home. For the person who lives alone, this may be a barrier. However, more hospice services are now able to make special arrangements for the dying person who lives alone (Michigan Hospice Organization, 1996).

In addition to physician attitude and knowledge as access issues, minorities are often disadvantaged due to their cultural beliefs on issues related to death and dying which may not be understood or accepted by hospices staffed predominantly by members of the white middle-class (Harper, 1995). Limitations to hospice access affect disadvantaged socio-economic groups because of restraints within the medicare regulations or patterns of healthcare utilization that differ from the mainstream American population. Gordon (1995) reported a built-in bias against minorities related to medicare regulations, such as the requirement of continuity of care entailing the availability of a primary caregiver. These limitations disproportionately affect blacks and Hispanics. Both groups are wary of hospice and the American healthcare system based upon past experiences (Kalish & Reynolds, 1975). Hispanics are especially critical of the lack of bilingual services (Gordon, 1995). Some of the barriers to minorities seeking hospice care are the lack of financial resources and adequate education, and the lack of targeted information for consumers and healthcare providers about hospice care in the non-white communities (Harper, 1995).

On the other hand, there are many factors that facilitate access to hospice, thereby decreasing the burden placed upon the primary caregiver, the health care professionals, and the family. Some of these facilitators to hospice access are not well known, and if better known, could make hospice use more widely accepted. Access to hospice care often involves significant cost savings to insurers over hospital care. Expenditures in the final month of life are 25%--40% lower for patients in hospice care compared to conventional hospital care; although cost savings may not be as high for long-term hospice services (Emanuel, 1996). Hospice can also provide better relief of pain and physical symptoms, as well as, taking an interdisciplinary approach to the

broader suffering that dying patients often experience (Jones, 1996; Michigan Hospice, 1996). Finally, hospice offers patients greater autonomy over end-of-life decisions (Emanuel, 1996).

Although the literature is limited on the discussion of access, it does touch upon issues related to diverse populations, professional dilemmas, and general lack of accurate information by all involved -- patient, family, and health professionals. To date, the bereaved "significant other" has not been involved in formally analyzing the issue of access.

This study focused upon the perceptions of bereaved "significant others" who had used hospice care. Twelve bereaved "significant others," most being family members, met and discussed the issues surrounding access to hospice care. This qualitative study analyzed the perceptions of close friends and family members of hospice patients, who reflected upon the hospice experience after the death of their friend or family member.

Methods

Design

The study design was qualitative, using focus group discussions. The discussions addressed issues surrounding access to hospice services experienced by "significant others" who were recently bereaved (mean 9.9 months). As an introduction to the group process, participants were asked to briefly reflect upon the time from when they first encountered the suggestion of hospice services for their loved one, through to the death. Based upon prior discussions with hospice staff, including administrators, nurses, social workers, and bereavement coordinators, regarding access issues, four broad open-ended questions were planned for the focus groups. In addition, a subset of more specific queries from each of the major questions were prepared to facilitate discussion. The four major problems were as follows:

1. Availability of Services--Describe any problems or difficulties you experienced in relation to the availability of hospice services.
2. Personal Issues--Describe any personal issues that hindered or delayed your access to hospice care for your family member or friend.
3. Financial Issues--Describe any financial concerns that kept you from using hospice sooner than you did.
4. Provider Issues--Describe any issues related to your doctors and/or nurses that might have kept you from using hospice services earlier.

Sample

An invitation to participate in the focus group discussions was mailed to a convenience sample of 40 recently bereaved (mean 9.9 months) individuals. Two hospice agencies in mid-Michigan participated in identifying 20 "significant others" who had used hospice services during their family member or friend's terminal illness. Of the 40 individuals identified, 22 responded to the invitation. Of those who responded, 12 were available at the time of the focus group sessions and consented to participate. Of those who responded but did not participate, several were on vacation during the June dates of focus group sessions, and two had moved out-of-state.

The sample was composed of 10 women and 2 men, ranging in age from early 20 to over 80 years of age. Half of the sample was over 65 years of age. All participants had lost a family member or friend recently (4 to 19 months ago, mean = 9.9 months). Nine of the participants had been the primary caregiver, and three had been a secondary caregiver. Relationships to the patient included wives (4), daughters (3), conjugal female friends of male partners (2), husbands (2), and a niece (1).

The participants were divided into two groups according to their availability. Each group consisted of six members, including one man in each group. One group was held at a local university, and the other group met at one of the participating hospice agencies. Each group met twice with a two-week interval between the two sessions.

Participants had utilized hospice services for their loved one for very short periods of time ranging from less than one week to two months - - far less than the potential six months. Eight participants had used hospice for less than three weeks. Educational levels varied among participants but were relatively high: four had a high school diploma, two had some college or trade school education, five had a bachelors degree, and one held a master's degree.

One patient received hospice care within a nursing home setting, and therefore her caregiver was the nursing staff. For the other patients, the caregiving was in the home, and provided by a female conjugal friend in three cases, the wife in four cases, a niece in one case, and the husband in three cases. It was interesting to note that, the two husband participants who identified themselves as the primary caregiver, frequently spoke of the help they received from their daughter and daughter-in-law. On the other hand, one of the participants who was a daughter to the patient, identified her father as the primary caregiver, even though, she gave many examples of the care she herself provided.

Procedures

Both sets of focus groups met for two, two and one-half hour sessions. All sessions were co-facilitated. One of the co-facilitators was a clinical nurse specialist with 15 years experience in all phases of oncology patient care, and extensive group facilitation experience. The other facilitator was a psychology doctoral student who had counseled women through a women's

resources center for several years. In addition to the two facilitators, two nurse research assistants greeted the participants as they arrived and offered them coffee and muffins. The research assistants also managed the tape recordings of the sessions. All sessions were recorded.

The sessions began with group-forming activities which included reviewing the informed consent that participants had signed, and offering self-introductions. Participants were also assured that any information provided would not be shared with the participating hospice agencies as individual comments, but only as group comments, if a report were requested.

The first focus group began with a discussion of the question related to availability of hospice services including barriers to access. From past experience with groups, the nurse facilitator decided that the participants would be least inhibited beginning with this area in a newly formed focus group. The second area of questioning during session one was related to personal issues surrounding the use of hospice. This area included probes that asked for discussion of family and social support around the barriers to access and their ultimate choice to use hospice. Two weeks later, the second session focused on the potentially more sensitive areas, including financial issues and access barriers related to health professions.

Analysis

Immediately after the sessions, the facilitators individually recorded observational notes, including preliminary themes that emerged during the group discussions. The facilitators then met to discuss these preliminary themes prior to the second sessions. Following the second sessions, the facilitators again met to briefly summarize their perception of potential themes.

Tape recordings of all four sessions were transcribed verbatim by a confidential transcription service, and reviewed for accuracy by one of the facilitators. The second facilitator

extracted sample sections from the transcriptions to spot check throughout to further substantiate the accuracy of the transcriptions.

Transcribed data were entered into the Ethnograph computer program. The co-facilitators initially worked independently with both the Ethnograph transcriptions and session notes to begin uncovering potential coding categories. In developing the codes, frequency of responses was taken into consideration. Investigators then met and shared their independently derived codes. Through comparing codes and discussing the content of each, consensus was reached on 15 coding categories.

The facilitators then followed procedures suggested by Krueger (1988) to identify themes from the 15 coding categories. Each facilitator analyzed the coding categories independently in search of the underlying themes. They then met to reconcile discrepancies. This often meant returning to samples of actual quotes to explain rationale for potential themes. Using an open verbal format, the facilitators were able to hear and take notes, and eventually consolidate themes. Initially, 10 themes were isolated. Then, through further discussion of overlaps, six major themes were captured. While only two themes directly focused upon access issues, recommendations for accessing hospice care were threaded throughout the themes. The focus groups provided far more information than access data. The themes that emerged will be presented first, followed by a discussion of access recommendations by the participants.

Themes

1. Societal and health system issues related to delayed access to hospice.
2. Education and practice needs of health professionals and social service workers, which affect hospice access.

3. Improved quality of life for patients with hospice support.
4. Benefits of hospice involvement for the caregivers.
5. Caregiver burden related to the dying process.
6. Unexpected experiences for caregivers during hospice care.

Results

Themes

Theme 1: Societal and health care system issues related to delayed access to hospice.

The categories that comprise theme one are as follows:

- a. Bureaucratic/societal barriers to accessing hospice.
- b. Public equating hospice with loss of hope and certain death.
- c. Caregivers' experiences with the transition from curative care to hospice care.

Theme one included comments concerning misconceptions about hospice, including payment and coordination of services; issues related to doctors serving as gatekeepers to hospice services; the American youth-oriented culture, which has difficulty confronting death, i.e., hospice care; and the caregiver's experiences in shifting from a life-saving mode to "comfort care" with hospice. Several of the participants' comments exemplify this theme as follows:

I think it is very difficult for doctors to recommend hospice; they don't like to make that decision for you that your loved one is only going to live another six months. They don't care to make decisions that may be wrong. You know, with lawsuits now days and doctors don't dare make mistakes now.

I don't know. I don't really see how you can dress it up and make it look any different. I mean, it is a terminal business really. And, terminal means the end.

Well if they could get more visiting nurses to go along with hospice to make a smoother transition like I had, instead of some visiting nurses setting themselves up against hospice for reimbursement reasons. It would be better if they all

worked together to make it easier to move from one kind of care to another when it was time.

Theme 2: Education and practice needs of health professionals and social service workers, which affect hospice access.

The categories comprising this theme were:

- a. Health professionals being too far removed from the death experience.
- b. Health professionals having difficulty letting go of the life process.

The categories for this theme consisted of issues surrounding the various health care professionals. Many participants believed that health professionals lacked knowledge or experience with the changes in a patient's status that indicate a serious decline in health, or perhaps they insulated themselves from acknowledging when it was time to shift away from their curative training. Along this same vein, there was a sense that health providers were out of touch with what was actually going on in the home, related to the needs of care. Finally, there was a line of dialogue that questioned health providers' comfort level with discussing death, and taking responsibility for determining when it was time to recommend hospice services. A sample of the comments contributing to this theme are as follows:

I mean, they [health providers] weren't close enough to a patient to see what they were really seeing when he [patient] came into the office. It [the office visit] is just so far removed from home care in that 15 minutes that they are allowed to see a patient.

At one point a young doctor suggested that, 'I hope you have religion'. That's an interesting way to put the prognosis. I think they are young and haven't been around like old family doctors have been.

They are there to cure and they just can't do the concept the other way around, so I don't think they can say, 'I failed,' you know.

There is a difference in doctors, and some doctors find themselves comfortable in talking to you and others don't. So if they don't play their part, there is a missing cog.

Theme 3: Improved quality of life for patients with hospice support.

This theme was composed of data coded into the categories of:

- a. Managing patient's physically distressing symptoms.
- b. Advantages of home death with hospice support for the patient.

These categories centered around the perceived benefits to the patient due to hospice care.

The participants expressed the ability to immediately address the distressing symptoms for the patient, and to maintain personalized care in familiar surroundings. Participants felt that the patient was able to maintain closer attachment to their caregiver and preserve the patient's privacy, dignity, and pride. Examples of these quality of life issues for the patient include:

I could face the facts when I had the opportunity of being there with him and him knowing that he was loved when he died, and not being in a cold impersonal atmosphere away from home.

In your own home, with our own porta potty to help him right away, and your people and your books and everybody around you, it seemed much better for him [patient], sleeping right there next to him in the night, you know, your own room and all.

Theme 4: Benefits of hospice involvement for the caregivers.

The fourth theme were composed of the following categories of data:

- a. Hospice responsiveness (service and supplies).
- b. Advantages to the caregiver of a home death with hospice.
- c. Hospice support for family and caregiver after death.

These categories clustered around the support hospice provided to the caregivers and other family members. The areas mentioned related the immediacy of hospice involvement once they were notified, in terms of providing services and supplies in the home; the continuity and control around care issues felt by the family; the cooperation and education hospice provided; the level of intimacy the family was able to maintain with the patient at home; and finally, the hospice support experienced after the home death. Examples of these benefits of hospice for the caregiver include:

Well, I was impressed, hospice set it up for us and I had no knowledge of hospice ahead of that, but boy they had it [hospital bed, supplies, etc] set up in about two hours time. We were all in business.

Hospice was there at the time [once contacted] and then they came every day to bathe him and just see if there was anything I needed and with the idea of staying with him if I wanted to go in to [town] get groceries or something.

They let me take care of things my way and without interference, and yet they were always there for me.

Well, one advantage of having hospice involved is that by calling them you can go around a couple of things. Because if you are not involved with them, and the death occurs, then law enforcement has to come to the scene to file a report. So you have police at your home at a difficult time.

She [hospice nurse] came to the funeral home; she was like one of the first ones that came to the funeral home. She has called and sent a couple of notes since then too. Very nice.

Theme 5: Caregiver burden related to the dying process.

Theme five consisted of the following categories:

- a. Patient symptoms contributing to caregiver burden.
- b. Caregiver realization of imminent death.
- c. Deterioration of caregiver's physical and emotional well-being prior to hospice services.

The fifth theme focused upon the difficulties experienced by the caregiver during the final days of the patient's life. The categories surrounding this theme consisted of issues such as dealing with the patient's physical symptoms and diminishing mental capacity; as the patient's death came nearer, the caregiver's inability to deny the imminence of the approaching death; and the caregiver feeling overwhelmed by the care requirements and fearing for his/her own physical and emotional health (generally prior to hospice intervening). The following examples highlight this theme:

I bought a commercial back brace, because when he got to be a dead weight, you know, I'm not a very big person, and of course, he'd lost pretty near 100 pounds, but he wanted me to do most things for him. He had lost his hair; he was a proud man and I know how he felt. And, not always knowing what was happening, especially at night he would get confused, so I had to stay near.

It is hard to watch them lay there and die. It takes a lot out of you. It's hardest to finally realize there is no getting better.

Well, it was just probably a week before he passed away. I had to go do this [make funeral arrangements]. Of course, he couldn't go with me. I took my Mom with me. But that was the hardest thing I had to do. I've told people; I say, talk about stuff like this with your husband, and do it together, don't wait like I did.

Hospice gave me a book. It tells what to look for so you know the body is shutting down gradually. I could visibly tell he was going down.

Hospice made my life liveable during that time; I was worn out in every way. They came in like saviors at that point.

Theme 6: Unexpected experiences for caregivers during hospice care.

The following two categories made up theme six:

- a. Caregiver social support from hospice in addition to patient care.
- b. Caregiver perception of subtle supportive services provided by hospice.

This theme was unanticipated by the investigator, but seemed to be a recurring topic. The caregivers felt they had been supported in ways that went beyond the official services of hospice, and this "extra" was part of what added meaning to their experience of a home death. The content mentioned in this theme addressed the personal and family growth experiences that developed as a result of utilizing hospice services. The following comments highlight this theme:

I think the nicest thing was that I had just been in to talk to him and he tried to talk and he said, 'love you,' and a tear went down his cheek. The nurse mentioned that he might not go [die] until I let him go. And I said, 'it is okay, honey, it is okay.' I walked out to the kitchen and when I came back in, he was gone.

It [hospice] was just like a magical experience; that's the only way to put it; emotional, caring, refreshing, everything...everything.

Once we had hospice, then my grandson helped. They showed him how to help grandpa. I really didn't think he could face up to it, but he didn't hesitate one bit. I was so proud of him. I was surprised. I think that's the nicest thing, when a family realizes that, golly, we can do this with a little outside help, you know, for Dad and we didn't think we could. It gives the family a closeness.

We were pleasantly surprised - - the hospice nurse was like a friend visiting. We always looked forward to her visits. She was so natural with us; uplifting and bright.

Discussion

Although the major probes of this study were designed to address access issues, the resulting six themes depicted the key experiences of bereaved loved ones, which included both access issues and the personal experience of participating in hospice care. Two of the six themes directly related to access, whereas the other four predominantly related to the hospice experience and only indirectly related to access. The hospice experience was clearly much more than access to these participants.

These results suggest that it is nearly impossible for people to go through the hospice experience and then to focus on just one aspect, such as initial access. It is a total and engulfing period of time, in which the objective, such as access, and the subjective, such as feelings and personal growth are intertwined and occur in unison. It is like a story that not only has a beginning (access), but also has both a middle and an end. In a focus group format such as this study, it was not possible to ask participants to tell only the beginning of their story. They did acknowledge that they were the lucky ones who had accessed hospice. They had hospice help through to the end, and in most cases, beyond to bereavement care.

Recommendations

Participants were asked to make specific recommendations for each of the major topic areas (see Table 1). It was initially difficult for the participants to suggest recommendations since they had had such positive experiences themselves with hospice. However, through discussion, they did generate a substantial collection of ideas to help others become familiar with and utilize hospice. Although the recommendations are grouped for purposes of presentation, there are many obvious overlaps between areas. The major groupings included general public recommendations to help the average person become more familiar with hospice. A second area dealt with "a sense of obligation" among those who had benefitted from hospice to share their experience. The professional education recommendation included ideas on how health professionals can become more knowledgeable about hospice to better position themselves to recommend the services. The provider recommendations addressed health providers taking more responsibility for being sure patients and families connect with hospice in a timely manner. The agency recommendations focused upon financial and political issues of accessing hospice care. And finally, the community

ideas centered around the various ways organizations and religious groups can better acquaint their membership with hospice. Many of the suggestions incorporated the preference to help people become aware of hospice services prior to a time of personal crisis, similar to the pre-planning suggested by many funeral agencies. Overall, the participants generated a broad variety of recommendations for increasing access to hospice through greater personal, public, professional and organizational awareness.

Methodological Considerations

This was a small, self-selected sample, which may introduce a possible bias into the sample. Self-selected samples can contribute to a pool of participants with a positive hospice experience, while eliminating those with a negative experience. Qualitative research such as this cannot be generalized to a larger population; rather, it can suggest trends. These trends can then later be tested for generalizability through larger quantitative research.

Despite the small sample size and limits to generalizability, this study had a number of strengths. The sequencing of questions worked well for the focus groups. Participants were comfortable with each other by the second meeting and willing to talk more about personal or private issues, which might not have occurred with just one meeting. Participants commented on feeling emotionally supported by this group experience. Although this was not a planned effect of the study, it did make the experience rewarding to the participants. Focus groups have been a natural format in various clinical setting when there is a need to elicit information in a non-threatening, supportive environment. The open-ended and non-suggestive questions sought responses directly from participants. Further, the descriptive qualitative methodology used was

appropriate as there is a paucity in the published literature related to access issues surrounding hospice.

Finally, the categories and themes that emerged may prove useful for the development of larger quantitative studies. For example, further examination is warranted related to access barriers and facilitators that families experience as they transition from curative to palliative care. Also, a better understanding of the positive aspects of home death, including bereavement services could be explored.

Through focus group discussion, this study has uncovered concepts not currently discussed in the literature. These concepts have the potential for making a critical addition to the study of bereavement, and to how health care providers can most effectively intervene for both the family and the patient during the dying process.

Hospice care comes out of a very deep commitment to serve life at the very time life is ending... It is about the re-definition of hope and helping people through a very difficult time of their life (Oncology News, 1997, p.38).

Hospice Focus Group Recommendations by Topic Areas

| Public | |
|---------------|--|
| 1. | More public awareness of hospice services and how to obtain. |
| 2. | Newspaper ads - full page; question and answer column. |
| 3. | Better public information on the costs that hospice covers. |
| 4. | Provide information on hospice before it is needed—not just at the end of life. |
| 5. | Clarify that hospice does not give up hope—currently signifies terminal to all. Create a health system where home care could transition to hospice care with more of a gray area, where it is still acceptable for the patient to improve, or to receive hospice care if the prognosis deteriorated. |
| 6. | Hospitals could send out health bulletins which include articles about hospice. |
| 7. | Clarification that hospice is not just for cancer patients. |
| 8. | Advertising: TV advertising during prime time; series of ads describing the various benefits of hospice (like the Taster's Choice coffee commercials): financial arrangements, caregiver support, respite care, general support for caregiver and family, and counseling. |
| 9. | Provide information on the benefits of home death for the patient—death with dignity, peaceful death, familiar surroundings, symptom management. |
| 10. | Provide information on the benefits of home death for the caregiver—greater control over care, availability, cooperation, education, support for caregiver and family to meet the burdens of care, and family cohesion. |
| 11. | TV and radio advertising could include both public broadcasting stations and community service ads on major network stations. |
| 12. | Provide information that some nursing homes can provide hospice care. |
| 13. | Inform public that hospice care is as much for the caregiver as for the patient. |

| Public, continued | |
|-------------------------------|--|
| 14. | Provide information on after death support—newsletters, bereavement groups, one-on-one talks, sharing meals. |
| 15. | Provide clarification about the six month prognosis, but that it can be extended or the contract can be broken if the patient improves. |
| 16. | Provide information that the family can avoid law enforcement coming to the home at the time of death—just call hospice. |
| 17. | Provide information on hospice homes for people without a primary caregiver. |
| Family/Caregiver | |
| 1. | Bereaved to share hospice experience in newspaper articles. |
| 2. | Word-of-mouth by bereaved recipients of hospice; mention hospice within one's circle of friends. |
| 3. | Former caregivers to work/volunteer for hospice; past caregivers to talk to community groups or one-on-one (this helps the caregivers feel like they are giving something back). |
| 4. | Encourage people to thank hospice in obituaries. |
| 5. | Encourage people to donate to hospice through obituaries. |
| Professional Education | |
| 1. | Educate staff at nursing homes regarding hospice. |
| 2. | Cancer doctors are more aware of hospice services/ similar training needed for all doctors and nurses. |
| 3. | Include hospice education in medical schools and nursing programs. |

| Health Professionals | |
|-----------------------------|--|
| 1. | Doctors and nurses need to be better educated on knowing when and how to introduce hospice to patient and caregiver. "Feel comfortable earlier giving information." |
| 2. | All health professionals and social service professionals need education on the role and function of hospice. |
| 3. | Health professionals need to take more responsibility for mentioning hospice services as part of the routine continuum of care. |
| 4. | Improve transition system for patient to more smoothly go from health care, to home care, to hospice care as appropriate. |
| 5. | Health professionals need to practice more holistically, with less denial of death and less heroic medical care and more focus on the reality of the prognosis. |
| 6. | Brochures and wall posters in providers' offices and waiting rooms. These should be very visible and direct about hospice care. |
| 7. | Provide TV programs in providers' waiting room areas regarding hospice services. |
| 8. | Doctors should sit in on hospice staff meetings. |
| 9. | Health professionals could be taught how to assist families to talk about dying with patients, i.e., making funeral arrangements, when to forgo heroic measures, discussion of the meaning of their life, spiritual issues, and unfinished business. |
| 10. | Health professionals could provide caregiver education one-on-one about signs and symptoms of impending death. |
| 11. | Health Professionals could provide information regarding the caregiver's evaluation of various hospices so that referrals are based on objective criteria. |

| Agency | |
|------------------|--|
| 1. | Health care agencies need to overcome the stigma of associating with the dying process, and the openly advertise hospice services as a component of the continuum of care. |
| 2. | Hospitals should have pamphlets available in public areas. |
| 3. | Encourage insurance companies to advertise hospice - less expensive than hospital care. |
| 4. | Mailings (HMOs, hospitals, hospice); newsletters from hospice, including hospice purpose, goals, and profiles on providers of hospice care. |
| 5. | A need for an ongoing evaluation of hospice services by caregivers to eliminate variations in quality of services. |
| 6. | Public clarification of the role of insurance carriers and patients' ability to receive hospice care, i.e., is a physician more likely to refer to hospice if the patient has full insurance coverage? |
| Community | |
| 1. | Encourage churches to include resource information on hospice (women's groups, sermons by minister or hospice staff person, Knights of Columbus - men's group) |
| 2. | Community organizations could provide speakers on hospice -- Farm Bureau, Rotary Club. |
| 3. | Publish a (coffee table/artistic) book for the general public with inspirational stories about people who have benefitted from hospice care. |
| 4. | Make available to the general public appealing CD ROMs with hospice information that could be utilized in their own home. |
| 5. | Provide home pages on the Internet on hospice services and local agency contacts. Provide past caregiver addresses to contact for one-on-one information. |

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**Physical and Psychosocial Outcomes of Midlife and Older Women
following Surgery and Adjuvant Therapy for Breast Cancer**

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Abstract

Purpose/Objectives: To investigate the patterns of functioning and psychosocial adjustment of midlife and older women following surgery for breast cancer. Differences between those who received follow-up adjuvant therapy and those who did not were also compared.

Design: 2 x 3 mixed design with one between-groups factor (type of treatment) and one within-subjects factor (time).

Setting: 4 Midwestern hospitals.

Sample: 46 breast cancer patients, aged 55+.

Methods: Baseline data about pre-surgical functional status and other variables were obtained during the first week after surgery. Follow-up data were obtained at 6-weeks, 3-months, and 6 months post-surgery. Data were collected via telephone interview and mailed questionnaire.

Main Research Variables: Functional status, patient symptomatology, quality of life, demands of illness, and type of treatment (surgery-only versus surgery-plus-adjuvant therapy).

Findings: There were no differences between the two treatment groups at baseline, with the exception of lower functional status reported by the surgery-only group. In the surgery-only group, functional status improved significantly from 6-weeks to 3-months post-surgery. The most frequently reported symptoms by both groups included fatigue and pain.

Conclusions: These results suggest that both groups did equally well regardless of whether they received adjuvant therapy (radiation and/or chemotherapy). Neither quality of life nor demands of illness differed between the two groups, nor did these scores change significantly over time following surgery.

Implications for Nursing Practice: These findings suggest that women undergoing surgery for breast cancer, whether they receive adjuvant therapy or not, may have functional and psychosocial needs that could be effectively addressed by nursing interventions pre- and post-surgery.

Physical and Psychosocial Outcomes of Midlife and Older Women

following Surgery and Adjuvant Therapy for Breast Cancer

Nationwide, the leading cause of death for women age 55 to 74 is cancer, and breast cancer is second only to lung cancer in its resulting mortality (Parker, Tong, Bolden, & Wingo, 1997). Incidence rates for breast cancer increase precipitously as women age. This risk increases to a 1 in 8 chance as women reach age 85 (National Cancer Institute, 1996). Further, there has been little evidence of a decrease in death rates from breast cancer in the last decade (American Cancer Society, 1997). Incidence rates continue to increase with age while survival rates remain unchanged.

Compounding these well-known statistics is the fact that surgery remains the first course of therapy for the vast majority of cases, and currently hospital discharges are down to less than 24 hours in many parts of the country. Millman and Robertson, the nation's leading consulting actuaries in health care, report that reduced breast cancer surgical hospital stays are the trend of the future, and that many of the surgical stays that now are considered standard will be recommended to be shortened or moved to outpatient services (Doyle, 1995). Although many women may be eager to get home, few realize until they are home what their post-surgical needs will be. Furthermore, older women, who were the focus of this study, may be more accustomed to an inpatient hospital stay following surgery and may have fewer resources and supports at home. As changes in discharge standards continue to evolve, it is imperative that nurses assess the physical and psychological needs of all women undergoing breast cancer surgery and treatment. This study investigated the patterns of functioning and psychosocial adjustment of midlife and older women (age 55 years and older) following surgery for breast cancer. Differences between those who received follow-up adjuvant therapy (chemotherapy and/or radiation) and those who did not were also compared. The intent was

to gain a better understanding of the effects of cancer treatment, to learn how to best promote active functioning and overall quality of life, while reducing the level and duration of limitations following treatment for breast cancer.

There is a lack of literature addressing the comparison between women who have surgery only and those who have surgery plus adjuvant therapy. The following review focuses on what is known about midlife and older (age 55+) women during the 6-month period following surgery for breast cancer.

Literature Review

Although the largest population affected by breast cancer remains the midlife and older women, there is an inverse relationship between age and the aggressiveness of treatment for breast cancer (Clark, 1992). Morrow (1994) found that failure to use adjuvant therapy (radiation and/or chemotherapy) when indicated is one of the most frequently identified problems in the management of older women with breast cancer. This finding was supported by Fleming and Fleming (1994), who reported that older women frequently are treated with less-than-standard therapy and are often excluded from clinical trials. However, it has been shown that older women tolerate adjuvant therapy as well as younger women (Fleming et al., 1994; Morrow, 1994; Solin, Schultz, & Fowble, 1995). Solin et al. (1995) concluded from evaluations of clinical trials that there is little empirical evidence warranting reduction or elimination of adjuvant therapy among women age 65 and older with breast cancer.

Although the medical research is clear on the efficacy and tolerance of surgery and adjuvant therapy in midlife and older women, investigators have not assessed the differences in functional status and quality of life between women who receive adjuvant therapy and those who do not. The

only body of literature that compares treatment differences addresses the use of surgery versus Tamoxifen alone (Fallowfield, 1994; Maher et al., 1995). Although it has been assumed by health professionals that women who receive adjuvant treatment will have more functional problems, symptoms, and lower quality of life, this assumption has not been substantiated by research (Solin et al., 1995). Investigators have only begun to assess changes in functional status and quality of life during the post-operative period that may inhibit women from returning to their pre-surgical health status. The current descriptive study provides information on trends among women who undergo breast cancer surgery, and compares those who received adjuvant therapy with those who did not have treatment beyond surgery.

Post-surgical care issues related to functioning and quality of life remain an under-investigated area of concern for women experiencing breast cancer. According to the Institute of Medicine (1993), after initial treatment, many women simply disappear from the health care system and do not receive continuing care that could help them cope with issues of survivorship or recurrence. Further, many questions remain about the optimal methods of delivering follow-up care.

In a discussion of issues in cancer rehabilitation, Ganz (1990) suggested that key components of a cancer transition program include an initial needs assessment with periodic reassessments, direct provision of specific services, and referrals to community resources. From the limited literature available, it appears that there are multiple post-surgical needs for midlife and older woman, including physical care needs, psychological concerns, sexual dysfunction, diet and nutrition questions, pain management, and vocational and economic problems. Finally, women in this age group tolerate adjuvant medical management of breast cancer far better than anticipated.

Study Aims

The specific aim of this project was to assess changes over time in functional status, symptomatology, quality of life, and demands of illness in women receiving only surgery for breast cancer versus those receiving both surgery and adjuvant therapy. Based on the medical outcomes literature related to older women and adjuvant therapy (Fleming et al., 1994; Morrow, 1994), it was expected that women would report no differences in psychosocial outcomes following surgery, regardless of whether or not they had received adjuvant therapy.

Methods

Sample

All participants (N=46) were female, 55 years of age or older, scheduled to receive surgical intervention for a diagnosis of breast cancer, and with no diagnosis of psychiatric or neurological disorder noted in their medical record. It was intended that the sample would consist of two groups of 20 women each: One group of women received no further treatment following surgery (other than possibly Tamoxifen), and a second group received adjuvant treatment (chemotherapy and/or radiation therapy). Ultimately, there were 30 in the surgery-plus-treatment group, and 16 in the surgery-only group. Data were collected from 6 additional women (beyond $n=40$) in an attempt to balance the groups. Although data were collected on specific combinations of post-surgery treatment (i.e., chemotherapy, radiation, chemotherapy and radiation, tamoxifen only, or none), due to the small sample size, these treatment groups were combined, as mentioned above, to conduct statistical analyses.

Participant Accrual

A nurse recruiter in each of the four Midwestern hospital sites recruited participants. The nurse recruiter reviewed the surgical log and identified those women scheduled for breast surgery who met the study's criteria. The nurse then contacted the women the morning after surgery (while still in the hospital), informed them about the study, requested their participation, and asked them to sign the consent form. The nurse recruiters mailed the signed consent forms to the investigator. All procedures were approved by the participating institutional review boards.

Procedures

Baseline data were intended to be collected by the nurse recruiter while the women were in the hospital; however, due to the very short hospital stays, often women were willing to participate but asked to be contacted at home for the baseline data. Therefore, all baseline data were collected during the first week following discharge. In these initial 10-minute telephone interviews, women were asked to recall their functional status 3 months prior to surgery. Additional data were collected by telephone interviews at 6 weeks, 3 months, and 6 months post-surgery, with the exception of the CaRES-SF instrument being administered via mail at 6 months post-surgery. Interviewers were graduate students in nursing or psychology, who received 10 hours of training and practice to standardize the interviewing procedures. The last three interviews averaged 45 minutes.

Data collection points. Data collection points were based on medical practice protocol for follow-up breast cancer therapy. Adjuvant therapy typically did not begin until 6 weeks post-surgery. Therefore, women were interviewed (Time 2) well into their surgical healing process but prior to adjuvant therapy. The third interview point was timed to occur during adjuvant therapy, and the fourth data point to follow adjuvant therapy.

Incentives

An incentive payment was offered to each woman to demonstrate the value of her time in responding to the questionnaires and interviews. After all four telephone interviews were completed, the list of actual participants' names and addresses was submitted to the budget office. Incentive checks for \$25.00 were then mailed to each woman.

Instruments

In addition to original items assessing demographic information, such as age, race, income, and marital status, four established instruments were used in this study.

Physical Outcomes

Functional status. Functional status was measured by an adapted version of the instrument from the Rand Health Insurance experiment and Medical Outcomes research (Ware et al., 1980). This 28-item instrument measured three dimensions of functioning: (a) Vigorous physical activities (9 items)--walking several blocks, climbing flights of stairs, bending, lifting, or stooping; (b) Balance and dexterity (9 items)--standing in place for 15 minutes, and writing or handling small objects; and (c) upper body self-care activities (10 items)--combing hair, washing upper back, and fastening a bra. This instrument was scored on a 0 to 2 scale, in which the "0" anchor equaled "not limited," and the 2 anchor equaled "limited a lot." The original measure of functional status has been tested for validity and reliability with reported alpha coefficients exceeding .90 (Jette et al, 1986; Stewart, Ware, & Barook, 1981; Ware & Sherbourne, 1992).

Respondents were asked via telephone interview to consider their functional status at four different time intervals, i.e., during the first week after surgery (by recalling their functional status 3 months prior to surgery), and then at three additional times post-surgically (at 6 weeks, 3 months,

and 6 months after surgery) to report their current functional status. Reliabilities (alphas) of the adapted instrument ranged from .85 to .94 across four times.

Symptomatology. The symptom measure, developed by Given et al. (1993), encompasses a two-component symptom experience index--the presence and severity of each symptom. Women were asked to report their symptom experience at the three post-surgical time intervals (6 weeks, 3 months, and 6 months post-surgery). Respondents reported the presence or absence of 23 symptoms and rated the severity of each. If a symptom were present, the participant then rated that symptom as "0" (mild), "1" (moderate), or "2" (severe). In previous research, each subscale had item-total correlations and coefficient alphas of above .90 (Given et al., 1993). In the current study, alphas on the presence/absence subscale ranged from .73 to .75 across three times. There were too few cases to analyze the reliability of the symptom severity subscale.

Psychosocial Outcomes

Quality of life. The Cancer Rehabilitation Evaluation System (CaRES-SF) (Schag & Heinrich, 1988), a reliable and valid instrument, was used to assess quality of life. The CaRES-SF is a comprehensive list of 59 problems encountered by cancer patients on a daily basis, consisting of five subscales: (a) physical functioning, (b) sexual functioning, (c) psycho-social functioning, (d) medical interactions, and (e) partnership interactions. Each item is scored as to its concern to the participant on a 5-point Likert scale ranging from "0" (not at all) to "5" (very much) (Schag & Heinrich, 1990). In previous research, alpha coefficients for the subscales ranged from .67 to .85 (Schag & Heinrich, 1988).

In the current study, respondents were asked about their quality of life at two times--6 weeks and 6 months post-surgery. The CaRES-SF was not used at the Time 3 interview due to reported

participant fatigue. However, it was mailed to participants at Time 4. Alphas were .98 and .94 for the full scale at Times 2 and 4, respectively.

Demands of illness (DOI). One subscale of the Haberman Demands of Illness Inventory (DOI) (Haberman, Woods, & Packard, 1990), a 125-item instrument with six subscales, was used to assess patient care and reactions to treatment. The 16-item subscale used in this study was entitled "treatment issues." Specific items in this subscale addressed: (a) relationships (health care providers have been insensitive, made decisions without my best interests in mind, not shown compassion for me as a person); (b) information exchange (wanted more information, felt rushed to make a decision, had questions to ask but couldn't); and © evaluation (been dissatisfied with treatment, worried that treatment may be wrong). All scales of the DOI have reported coefficient alphas of .70 or greater, with an alpha of .98 for the "treatment issues" subscale (Haberman et al., 1990). Although this instrument has primarily been tested with chronic populations, it has also been used with women recently diagnosed with breast cancer (Haberman et al., 1990).

Respondents were asked to report on their perceived demands of illness at all three post-surgical times (6 weeks, 3 months, and 6 months post-surgery). Alphas ranged from .79 to .92 across the three times.

Results

The original hypothesis was supported by the data, in that the two groups of women reported similar psychosocial and physical outcomes post-surgically, regardless of whether they had received adjuvant treatment. Data from the two groups of women were compared at each time, and the only significant difference found was in baseline functional status (3 months before surgery). Therefore,

results from the two groups are reported separately only when findings were significant or unique to one group. Statistical analyses were performed using SPSS for Windows.

One-way analyses of variance (ANOVAs) by treatment group were performed for each continuous demographic variable. (Please refer to Table 1 for demographic information.)

Demographically, there were no significant differences between the two groups, other than age ($F(1,44)=6.71, p<.01, n=45$). The surgery-plus-treatment group ranged in age from 57 to 81, with a mean age of 69 years. The surgery-only group ranged in age from 55 to 89, with a mean of 75 years. Half of the women in the surgery-only group received Tamoxifen, and the majority of women in the surgery-plus-treatment group received radiation therapy.

Of the total sample, the majority of the women were Caucasian (97%), married, retired, and had a high school education. Approximately half of the women had an annual household income of under \$22,000; the other half reported annual incomes greater than or equal to \$22,000. To assess possible effects of income, repeated measures ANOVAs (analysis of variance) by income group were performed for each outcome variable. With baseline functional status held constant (as a covariant), women with higher annual incomes (\$22,000 and above) reported higher quality of life at both 6 weeks and 6 months post-surgery than did lower income women ($F(1,27)=4.08, p<.05, n=28$). In addition, women with higher incomes reported significantly higher functional status across all four times ($F(1,28)=7.13, p<.01, n=29$).

Functional Status

The 28 functional status items were measured at all four points of assessment, i.e., 3 months prior to surgery (via recall), 6 weeks after surgery, 3 months after surgery, and 6 months after surgery. Functional status scores ranged from "0" (no limitation) to "2" (yes, limited a lot). A

repeated measures ANOVA was performed for functional status by treatment group. Mean functional status scores by group over time are presented in Table 2. There was a significant between-group difference at baseline in that the surgery-plus-treatment group reported higher functional status than the surgery-only group ($F(1,42)=3.96, p<.05, n=43$). Because there was a significant difference between the two groups in baseline functional status, changes over time in functional status were examined by repeated measures ANOVAs for each group separately. In the surgery-plus-treatment group, functional status decreased significantly from before surgery to 6 weeks post-surgery ($F(1,27)=8.35, p<.01, n=28$). This decrease in functioning was still evidenced at both 3 months and 6 months post-surgery. In other words, the women who received further treatment did not regain their pre-surgical functioning by 6 months after surgery ($F(1,27)=6.35, p<.05, n=28$); they never returned to their pre-surgery functional level. For the surgery-only group, there were no significant changes in functional status over time from baseline to 6 months.

However, when baseline functional status was held constant, functional status for the surgery-only group improved significantly from 6 weeks to 3 months post-surgery ($F(1, 9)=6.82, p<.05, n=10$) (see Table 2). The areas in which women reported the greatest improvement were pushing heavy objects, lifting and carrying groceries, and lifting over 10 pounds.

A repeated measures ANOVA was also performed for functional status on the entire sample. There was a significant time effect for functional status from baseline to 6 weeks post-surgery: Both groups reported significantly yet comparably decreased functioning at 6 weeks after surgery ($F(1,36)=7.95, p<.01, n=37$). At 6 weeks post-surgery, all women reported the greatest limitations in the following activities: vigorous activity, walking more than one mile, pushing heavy objects, lifting over 10 pounds, carrying groceries, and climbing flights of stairs. Further, when looking at the

sample as a whole, there was a significant difference between baseline functional status and functioning six months post-surgery ($F(1, 40)=4.23, p=.05, n=42$), suggesting that the women did not return to their pre-surgery level of functioning by six months after surgery.

Symptomatology

Symptoms were measured at three time intervals--6 weeks, 3 months, and 6 months after surgery. Of the 23 symptoms assessed, the most frequently reported by the total sample were cancer related pain, trouble sleeping, fatigue, difficulty breathing, dry mouth, urinary frequency, weakness, and loss of feeling. Each symptom was further defined by the perceived degree of severity (i.e., mild "0", moderate "1", or severe "2").

Symptoms were analyzed for each participant group separately to capture any possible differences due to adjuvant therapy (see Table 3). In the surgery-plus-treatment group, pain and fatigue were the most frequently reported symptoms at all three times. At 6 weeks after surgery, pain was most frequently reported as mild (mean=.69, range=0-2); at 3 months, pain was primarily moderate (mean=.88), and at 6 months, pain was mainly mild again (mean=.56), with only 7-10% of the women reporting severe pain at any given time. Fatigue was reported by the majority of women at all three assessment points. Fatigue was perceived as mild to moderate (means ranged from .62 to .88), with 10-17% of the women reporting severe fatigue over the three post-surgical times. Although women reported relatively low levels of severity on pain and fatigue, these symptoms did not improve over time. However, differences between the two groups were unable to be analyzed statistically due to small cell sizes.

In the surgery-only group, pain and fatigue were also the most frequently reported symptoms at all three post-surgical times. Mean pain scores were .67, .75, and .33 at each time respectively.

Mean fatigue scores were .29, .80, and .67 at each post-surgical time. However, neither of these symptoms was reported by the majority of this group (see Table 3 for specific percentages across time). The highest percentage of women reported pain as a mild to moderate concern, with only 6% reporting pain to be a severe symptom. With regard to fatigue, the highest percent of women reported fatigue as a mild to moderate concern, with only 6% classifying it as a severe symptom at any assessment point.

Quality of Life (QOL)

Quality of life was measured at two time points--6 weeks and 6 months after surgery. A repeated measures ANOVA of quality of life by treatment group was performed. With baseline functional status held constant, there were no significant differences between groups at either time ($F(1,32)=.38, p=.55, n=33$), and no significant change over time ($F(1,33)=1.88, p=.18, n=34$). The non-significant trend for both groups was toward a decline in QOL from 6 weeks to 6 months following surgery; however, mean scores on the CaRES-SF ranged from "0" (not at all a concern) to "2" (a moderate concern) on a 0-4 scale. The women as a total sample reported the lowest quality of life on the sexuality subscale, which included items related to sexual interest and dysfunction (see Table 4).

Demands of Illness (DOI)

Demands of illness were assessed at the three post-surgical times. A repeated measures ANOVA by group was performed for demands of illness. With baseline functional status held constant, there were no significant main effects of group or time for demands of illness. As a total sample, the women reported a non-significant, but continual decrease in their demands of illness over the three times. However, mean scores on the Demands of Illness Inventory items ranged from "0"

(not a problem at all) to "2" (a moderate problem) on a 0-4 point scale. The two most frequently reported areas at all assessment times were also the most problematic for the women: These items related to wanting more information than was provided by health care professionals, and wanting to know why various treatments were being done. Among women who expressed these concerns, the highest percentage reported "extreme" concern about these two areas (see Table 5).

Correlational Analyses

Correlational analyses were performed to examine relationships among composite scores of outcome variables in the sample as a whole. At 6 weeks post-surgery, quality of life was positively associated with functional status ($r=.66, p<.001$), and negatively correlated with demands of illness ($r=-.51, p<.001$). At 6 months after surgery, functional status was positively correlated with quality of life ($r=.40, p<.05$), and negatively correlated with demands of illness ($r=-.38, p<.01$). Demands of illness were also negatively correlated with quality of life ($r=-.54, p<.001$) at 6 months after surgery.

Discussion and Implications

Overall, the most noteworthy findings were the frequent reporting of specific symptoms (pain and fatigue), the significant difference between groups at baseline in functional status, and the significant decline in functional status after surgery, which was never fully regained by the group as a whole. Although quality of life was relatively high, and demands of illness were relatively low at all time intervals measured, the trends remain interesting with a decline in both over time. In addition, income was significantly related to quality of life and better functioning across all times.

In exploratory work such as this, it is often useful to evaluate specific items as well as overall scales or subscales. The specific items provide information to guide the practitioner in actually determining which interventions are most needed for a population (Ferrell, 1996). Therefore, this

report has made a point to consider individual items of clinical interest, as well as composite scores on scales and subscales.

Because three of the functional limitations reported (pushing heavy objects, lifting over 10 pounds, and carrying groceries) may be related to upper body strength, pre-operative teaching could be done to teach the range-of-motion arm and shoulder exercises traditionally recommended after breast surgery (American Cancer Society, 1996). Such exercises could help strengthen the muscle groups prior to surgery, while also helping women establish a pattern of exercise before surgery. Pre-surgical strengthening may help women feel that they are participating in their own health promotion during a time when they often feel helpless and anxious (Northouse, 1992). The exercises could help dissipate their anxiety while building muscle groups that need to be maintained after surgery. Moreover, the pattern of exercise would be in place and be easier to reinforce, rather than teach, after surgery.

Across both groups of women, the remaining three functional limitations (vigorous activity, walking more than one mile, and climbing flights of stairs) were related to endurance. The creation of exercise programs, such as those targeting walking, could help women build endurance after surgery (Mock et al., 1994). Also, women who participate in exercise programs often report a more positive outlook after breast cancer surgery (McCaughan & Sexton, 1991). In addition, exercise programs may prevent the trend observed in this study toward a further decline in functional status 6 months after surgery. Rather than encouraging breast cancer survivors to "take it easy," perhaps nurses should recommend moderate exercise to improve endurance and a sense of well-being (Winningham, 1989).

As pain and fatigue were the two most frequently reported symptoms, nurses need to know more about these symptoms in women with cancer post-surgery. A thorough assessment is necessary to determine the location of the pain, factors that alleviate or aggravate pain, and the actual quality of the pain. Along with physical factors, nurses need to assess related emotional factors, such as fear of recurrence of cancer, changes in interpersonal relationships since surgery, and anxiety about adjuvant therapy. Nurses must remember that pain is more than a physical response, and for women with breast cancer, pain is certain to be multifaceted (Ferrell, 1991).

It may also be helpful to assess which other symptoms are associated with fatigue. Perhaps sleep pattern disruption, pain, upper body weakness, or changes in family roles are related to fatigue, and need to be treated first or in conjunction with fatigue (Winningham et al., 1994). Further, it would be interesting to determine if various psychological states or other factors are related to fatigue, such as depression, unemployment, or other concerns. If such patterns in symptoms emerged, it would be reasonable to expect an intervention such as exercise to not only improve endurance and upper body strength, but also to help elevate a depressed mood or provide the physical activity needed to get a restful night's sleep (Mock et al., 1994). It is also noted that for the small but important percent of women who reported severe fatigue, perhaps sitting outdoors would be the first step toward exercise, and could serve as an activity that may prove emotionally refreshing (Nail, 1996).

The two most prominent demands of illness for this sample were related to information. In response to this identified need, nurses can become more creative in how they provide information, and in how to provide it in a shortened time frame, with same-day surgery the norm. The fact that demands of illness decreased (although non-significantly) over time suggests that women's need for

more information is greatest immediately following surgery. Telephone hotlines staffed by nurses to answer post-surgical questions could be implemented as a mechanism for patients to stay connected with health care resources after discharge (Love, Wolter, & Hoopes, 1985). Women may feel rushed out of the medical system, unprepared to care for their own physical needs and emotions. Further, support groups can provide an excellent informal information network (Wyatt & Friedman, 1996). Perhaps more personalized invitations to attend would increase attendance, along with focused discussions to address the issues of the women newest to the breast cancer experience (Samarel, 1992).

Because sexual concerns were reported highest among concerns affecting quality of life, nurses could assess whether couples classes or group discussions may be beneficial. A safe environment could be created for both members of the couple to discuss their issues and feelings. Although untested to date, classes could integrate both heterosexual and lesbian couples, or groups could be separated into same-sex and heterosexual couples. Classes could incorporate homework exercises, such as viewing the surgical area together, touching the area, or engaging in open discussions about how their sexuality has been affected by the cancer (Sabo, Brown, & Smith, 1986). Also, it is often appropriate to introduce some of the complementary therapies to couples, such as massage or therapeutic touch, to help partners reconnect in a non-threatening and nurturing way (Carrathers, 1992). Ideally, the couples groups could begin prior to surgery, when the anxiety level is often high for both members of the couple (Northouse, 1992). This way, couples who had gotten through the pre-surgical time could help support the newly-diagnosed couples. It might also be useful to reframe the support group concept by calling it a seminar or another alternative term that might sound more appealing to men (Northouse, 1993). Men may also respond positively to a

discussion about "team-building" between the two members of the couple, a concept commonly used in business settings.

The descriptive findings that higher income was significantly related to quality of life and higher functional status are worth noting. These results suggest that a woman's pre-surgery resources may determine how well she recovers from breast cancer surgery and treatment. Higher-income women may be better able to pay for services to hasten their recovery and improve their quality of life. These findings also support the importance of especially targeting lower-income women for the interventions suggested herein.

Finally, several limitations in research methodology should be acknowledged. Clearly, the sample of 46 women is relatively small and homogeneous, and one cannot generalize these results to the larger population of breast cancer patients. Participants were not randomly selected or randomly assigned to treatment groups, which further decreases generalizability. The sample may be less than normal in terms of distribution, which may be responsible for the high variability in scores on the quality of life measure. This high variability may explain why no significant differences between groups were detected. Also, it was necessary to combine participants receiving various treatments to obtain large enough groupings for analysis. Ideally, women who received only radiation or chemotherapy would be analyzed separately to distinguish differential effects of each intervention. Similarly, it would be preferable not to combine women taking Tamoxifen, who may have experienced some drug side effects, with women who did not have any further treatment after surgery. In addition, type of surgery and choice regarding treatment were not evaluated as variables. Perhaps women who were given a choice as to type of surgery and treatment they received responded differently. Further, while the surgery-only group more fully regained their pre-

surgical functional status, they were significantly older than the surgery-plus-treatment group, so age may have been a factor accounting for the difference in baseline functional status. With regard to instrumentation, the psychosocial measures used included a three-month recall for baseline data on functional status, which may affect the accuracy of the data. In addition, all instruments were self-reported measures, which may be influenced by demand characteristics (responding to "please" the investigator) or social desirability pressures.

Further research is needed to assess the needs of, and outcomes for, larger numbers of breast cancer surgery patients. Future research would also benefit from prospective data collection prior to surgery and from the use of various data collection techniques, including functional or fitness testing to allow multi-method validation of the results. That is, outcome measures could be assessed more diversely (via interview, various questionnaires, functional testing) to cross-validate the results with data from a variety of sources.

Although we have suggested various interventions to address specific post-surgical needs of breast cancer patients, these interventions will likely benefit multiple areas of concern. For example, exercise programs, support groups, and information hotlines may act together or additively to help allay possible fatigue, pain, lack of medical information, and concerns about sexuality. These intervention components could be made available to women independently, or as an integrated post-surgical package of follow-up services. Further clinical outcomes research will be necessary to evaluate the effects and effectiveness of such interventions.

Table 1

Demographics

Total Sample (n=46)

| Variable | n | % |
|--------------------------|----|------|
| Ethnicity | | |
| Caucasian | 45 | 2.2 |
| African-American | 1 | 97.8 |
| Marital Status | | |
| Single | 2 | 4.3 |
| Married | 23 | 50.0 |
| Widowed | 18 | 39.1 |
| Divorced | 3 | 6.5 |
| Employment Status | | |
| Work outside home | 8 | 17.4 |
| Unemployed | 24 | 82.6 |
| Did not respond | 14 | 30.4 |
| Education | | |
| Grade school | 1 | 2.2 |
| Some high school | 3 | 6.5 |
| High school graduate | 20 | 43.5 |
| Some college | 13 | 28.3 |
| College graduate | 3 | 6.5 |
| Grad/Professional | 6 | 13.0 |
| Treatment | | |
| Chemotherapy | 6 | 13.0 |
| Radiation | 22 | 47.8 |
| Chemo & radiation | 2 | 4.3 |
| Tamoxifen only | 8 | 17.4 |
| No post-surgery tx | 8 | 17.4 |

| Variable | N | M | SD | Range |
|---------------|----|----------|----------|----------------|
| Income | 46 | \$28,157 | \$19,052 | \$5,000-62,500 |

| By Group | Group 1 - Surgery & Tx | | | | Group 2 - Surgery | | | |
|------------|------------------------|-----|----|-------|-------------------|-----|----|-------|
| Variable | n | M | SD | Range | n | M | SD | Range |
| Age | 30 | 69* | 6 | 57-81 | 16 | 75* | 8 | 55-89 |

*significantly different at $p < .05$

Table 2

Mean Functional Status by Group over Time

| Time | 3 Months before Surgery | | 6 Weeks after Surgery | | 3 Months after Surgery | | 6 months after surgery | |
|----------------------------|----------------------------|-------|--------------------------|-------|---------------------------|-------|---------------------------|-------|
| | 1 | | 2 | | 3 | | 4 | |
| Group | M | (SD) | M | (SD) | M | (SD) | M | (SD) |
| 1 (Surgery & Tx) (n=30) | .18** | (.20) | .33** | (.37) | .33 | (.41) | .33 | (.42) |
| 2 (Surgery Only) (n=16) | .35* | (.35) | .52 ^a | (.46) | .32 ^a | (.42) | .41 | (.43) |

Range=0-2

*Significant between group difference at $p < .05$.**Significant within group over time difference at $p < .05$.^aSignificant within group over time difference with baseline held constant at $< .05$.

Table 3

Percent of Women Reporting Pain and Fatigue across Time

| <u>Assessment Times after Surgery</u> | | | | | | |
|---------------------------------------|-------------------------|---------|---------|---------------------|---------|---------|
| | <u>Group 1</u> | | | <u>Group 2</u> | | |
| | <u>Surgery & Tx</u> | | | <u>Surgery Only</u> | | |
| | n=30 | | | n=16 | | |
| | 6 Week | 3 Month | 6 Month | 6 Week | 3 Month | 6 Month |
| Pain (Total) | 43% | 57% | 54% | 19% | 25% | 38% |
| mild | 23% | 17% | 30% | 13% | 13% | 25% |
| moderate | 10% | 30% | 17% | 6% | 6% | 13% |
| severe | 10% | 10% | 7% | --- | 6% | --- |
| Fatigue (Total) | 70% | 53% | 56% | 44% | 32% | 38% |
| mild | 37% | 23% | 23% | 31% | 13% | 19% |
| moderate | 23% | 13% | 23% | 13% | 13% | 13% |
| severe | 10% | 17% | 10% | --- | 6% | 6% |

Table 4

Quality of Life Subscale and Total Means for Total Sample.

| | 6 Weeks after Surgery (n=39) | | | 6 Months after Surgery (n=42) | | |
|--------------|------------------------------|------|--------|-------------------------------|------|--------|
| | M | SD | Range | M | SD | Range |
| Medical | .19 | .58 | 0-3.5 | .28 | .70 | 0-3.75 |
| Marital | .26 | .42 | 0-1.7 | .35 | .36 | 0-1.33 |
| Psychosocial | .45 | .49 | 0-2.4 | .60 | .64 | 0-2.71 |
| Physical | .55 | .58 | 0-2.4 | .63 | .73 | 0-3.38 |
| Sexual | 1.03 | 1.23 | 0-4.0 | 1.11 | 1.31 | 0-4.00 |
| Total | .47 | .44 | 0-2.39 | .58 | .61 | 0-3.12 |

range=0-4

Table 5

Percent of the Two Most Frequently Reported Demands of Illness by Severity for Total Sample

| <u>Demands of Illness Items</u> | <u>Assessment Times after Surgery</u> | | |
|---------------------------------|---------------------------------------|----------------|----------------|
| | <u>6 Week</u> | <u>3 Month</u> | <u>6 Month</u> |
| Wanted more facts (Total) | 31% | 24% | 31% |
| a little | 9% | 2% | 7% |
| moderate | 7% | 11% | 7% |
| quite a bit | 2% | 4% | 4% |
| extremely | 13% | 7% | 13% |
| Wanted reason why (Total) | 42% | 38% | 37% |
| a little | --- | 2% | 4% |
| moderate | 7% | 9% | 11% |
| quite a bit | 13% | 7% | 2% |
| extremely | 22% | 20% | 20% |

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Ware, J.E., & Sherbourne, C.D. (1992). A 36-item short form health survey (S-36). Medical Care, 30(6), 473.

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A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

PRODUCTIVITY REPORT
Appendix E

*A Subacute Care Intervention
for
Short-Stay Breast Cancer Surgery*

September 15, 1996 to September 14, 2000

Productivity Report

Funded by

U. S. Army Medical Research
Materiel Command
Department of Defense

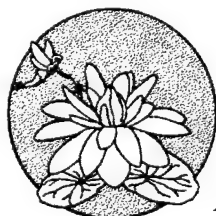
Principal Investigator:

Gwen Wyatt, RN, PhD
Associate Professor
College of Nursing

Co-Principal Investigators:

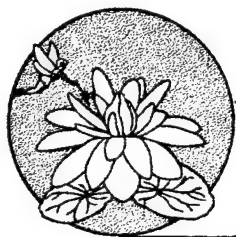
Barbara Given, PhD, RN, FAAN
Professor, College of Nursing
Director of Research,
Institute of Managed Care
Associate Director, Cancer Prevention
and Control, MSU Cancer Center

Charles Given, PhD
Professor, College of Human Medicine
Associate Chair for Research
Family Practice



A New Beginning

*Michigan State University
East Lansing, Michigan 48824*



Nursing Care for Breast Cancer Staff Productivity

Fall 1996 through Summer 1997

PUBLICATIONS

Wyatt, G., Kurtz, M. E., Given, B. A., Given, C., & Friedman, L. L. (1997) Preliminary Listing of the Long-Term Quality of Life (LTQL) Instrument for Female Cancer Survivors, Journal of Nursing Measurement, 4(2).

Given, B.A. (1997). Response to "Caregiver Concept Analysis Outcomes." Scholarly Inquiry for Nursing Practice: An International Journal, 11(1), 75-78.

Given, B.A., Given, C.W., Helms, E., Stommel, MN., & DeVoss, D.N. (1997). Determinants of Family Caregiver Reaction: New and Recurrent Cancer. Cancer Practice, 5(1), 17-24.

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MANUSCRIPTS ACCEPTED (in press)

Given, B.A., Given, C.W., & DeVoss, D.N. (in press). The Education of Nurses for the Future: Caring for Those with Chronic Health Care Problems. In V. Ferguson (Ed.), Culturally Sensitive Care in the Community.

MANUSCRIPTS SUBMITTED

Given, B.A. & Given, C.W. (1997, January) Health Promotion for Family Caregivers of Chronically Ill Elders. Manuscript submitted for inclusion in J.J. Fitzpatrick (Ed.), Annual Review of Nursing Research (vol. 16).

Wyatt, G. & Friedman, L. (submitted 9/97 for final review) Physical and Psychosocial Outcomes of Midlife and Older Women Following Surgery and Adjuvant Therapy for Breast Cancer. Oncology Nursing Forum.

Wyatt, G. & Ogle, K. (Submitted 8/97). Improving access to hospice care: A perspective from the bereaved. Journal of Palliative Care.

| |
|----------------------|
| PRESENTATIONS |
|----------------------|

Given, B. (1996, September 18). Family Home Care for Cancer -- A Community-Based Model of Care. Poster presentation at the Friends of the National Institute of Nursing Research, "Science in Service to the Nation's Health" Congressional Open House, Washington, DC.

Given, B. & Siegl, E.J. (1996, October 1). Cancer in Women: An Overview. Presented at the Issues for Women with Cancer Faculty Seminar Series, co-sponsored by the Cancer Center at MSU, College of Nursing, Department of Family Practice, Michigan State University, East Lansing, MI.

Given, B. (1996, October 11). Today's Chaos is Tomorrow's Opportunity. Paper presentation and moderator at the "Challenges of Advanced Nursing Practice in Today's World: Practitioners Defining their Roles" MSU College of Nursing Homecoming Conference, Kellogg Center, East Lansing, MI.

Given, B. & Given, C.W. (1996, October 22). Alternation in Family Role. Presented at the Issues for Women with Cancer Faculty Seminar Series, co-sponsored by the Cancer Center at MSU, College of Nursing, Department of Family Practice, Michigan State University, East Lansing, MI.

Given, B.A., & Given, C.W. (1996, October 25). Rural Partnership Linkage for Cancer Care. Progress report to the National Cancer Institute, Washington, DC.

Wyatt, G. (1996, November) New DOD Funding for Breast Cancer Transition Care Research. College of Nursing, Research Center Seminar Series, East Lansing, MI

Given, B. (1997, January 23 - 25). Considerations in Designing Nurse-Sensitive Indicators in Outcomes Research: Models of Care. Symposia presentation at the Fourth National Conference on Cancer Nursing Research, Panama City, FL.

Wyatt, G. (1997, January 23 - 25). Physical and psychosocial needs of midlife and older women following surgery and adjuvant therapy for breast cancer. Fourth National Conference on Cancer Nursing Research, Panama City, FL.

Given, B. (1997, February 18). The Family Caregiver: The Hidden Patient. Visiting Professor presentation at the Marlene and Stewart Greenebaum Cancer Center, "The Director's Conference Series," Baltimore, MD.

Given, B. (1997, March 11) Continuing Needs of Elderly Cancer Patients After Diagnosis. Paper presentation at Sparrow Regional Cancer Center Meeting, Sparrow Hospital, Lansing, MI.

Presentations, continued

Wyatt, G. (1997, May 3). Preliminary Testing of a Long-Term Quality of Life Instrument. Poster presentation for Oncology Nursing Society Congress, New Orleans, LA.

Given, C.W. (1997, May 6) Impact on Physical Functioning of Initial Treatment for Older Patients with a New Diagnosis of Breast, Colon, Lung, and Prostate Cancer. Presentation at the Medicine Grand Rounds, Sparrow Hospital, Lansing, MI.

Given, C.W. (1997, May 21). Impact on Physical Functioning of Initial Treatment for Older Patients with a New Diagnosis of Breast, Colon, Lung, and Prostate Cancer. Presentation at the Michigan Association of Local Health Officers, Michigan Department of Community Health, Lansing, MI.

Given, B.A. (1997, June 4 - 6). Building a Program of Research. Presentation at the Cancer Prevention & Control Program, Cancer Center, University of Nebraska, Omaha, NE.

Given, B. (1997, June). Cancer in the Aging Population. Invited paper presentation at the President's Cancer Panel, University of Michigan, to be held July 31, 1997, in Ann Arbor, MI.

Given, B. (1997, August 6). Managed Care Educational Opportunities. Presentation at the Michigan Primary Care Association 18th Annual Meeting and Board Training Conference "managing Change with 'Care' II," Traverse City, MI.

Given, B. (1997, August 28 - 30). Health Promotion in a Managed Care Environment. Presentation at a plenary session at the University of Iowa conference, "Vitality Throughout the Adult Lifecycle: Interventions to Promote Health," Iowa City, IA.

| |
|---------------------------|
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|---------------------------|

Wyatt, G. (1997, May). Era of Hope: A multidisciplinary reporting of DOD progress. Abstract accepted for poster presentation at the Department of Defense Breast Cancer Research Program Conference to be held October 31 - November 4, 1997 in Washington D. C.

Wyatt, B. (1997) Physical and psychosocial needs of midlife and older women following surgery and adjuvant therapy for breast cancer. Fourth National Conference on Cancer Nursing Research Abstract Book, p. 90.

Given, B. (1997, June). Patient & Family as Partners in Care: Is Education the Answer? Abstract accepted for presentation at the 8th Annual Home Care Conference, Medical College of Ohio, to be held October 16, 1997, in Toledo, Ohio.

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Given, B. (1997, August). Impact and Interaction of Age, Comorbidity Site, Stage of Cancer on Change in Physical Functioning Following Diagnosis of Cancer in Older Patients. Abstract submitted to the 23rd Annual Congress of the Oncology Nursing Society to be held in San Francisco, CA, May 7- 10, 1998.

Wyatt, G. (Submitted August 15, 1997). Bridging the Gap Between Nursing Outcomes and the Research Process: One-step Computerized Documentation and Direct Data Entry. Abstracts submitted to the 23rd Annual Congress of the Oncology Nursing Society to be held in San Francisco, CA, May 7- 10, 1998.

INVITATIONS EXTENDED

Wyatt, G. (1997, January) Breast Cancer: Post-Surgical Care. Invited speaker for Great Lakes Nursing Cancer Conference to be held October 21, 1997, Novi MI.

CONSULTATIONS

Given, B.A. (1997, June). Cancer Prevention & Control Program, Cancer Center, University of Nebraska - Omaha.

GRANTS

Wyatt, G. (Principal Investigator), Given, C., & Given, B. (Co-principal Investigators). (Submitted 9/13/95). A Subacute Care Intervention for Short-Stay Breast Cancer Surgery. Funded 9/15/96 by the Department of Defense, grant #DAMD17-96-1-6325 (4 year budget \$799,558).

Given, B., Slomin, A., Wadland, W., & Given, C.W. (1996, August). Cancer Prevention, Outreach and Access to Care for the State of Michigan. Funded by the State of Michigan, Department of Community Health, Community Public Health Agency. (Total budget \$1,000,000.)

Given, B., Champion, V., & Given, C.W. (9/1/96 - 8/31/98). Cancer Case Intervention to Improve Functioning and Psychosocial Outcomes in Newly Diagnosed Cancer Patients and Their Families. Funded by the Mary Margaret Walther Cancer Care Program, Indiana University. Total budget \$250,903.

Given, B., Mutch, B., Wadland, W., & Given, C.W. (1997, Oct. 1 - Sept. 30, 1998). Care, Prevention, Outreach and Cancer Control (Supportive Care) for Cancer Patients . Funded by the State of Michigan, Department of Community Health. (Total budget \$1,000,000.)

GRANTS SUBMITTED

Given, B., & Given, C.W., Family Home Care for Cancer -- A Community-Based Model. (1997, March 1). Grant submitted to the National Institute for Nursing Research. (Total budget: \$2,389,990.)

POLICY STATEMENTS

Given, B.A. & DeVoss, D.N. (1996, October). Pain, Depression, and Medication. Vol. 6, Ed. 4.

Given, B., Given, C.W., & DeVoss, D.A., Birkmeier, J. (1997, March). Working Toward Comprehensive Assessment of the Family Care Situation, Vol. 7, Ed. 1.

LAY ARTICLES, LAY PRESENTATIONS AND MEDIA

Wyatt, G. (1996, October). Sigma Theta Tau Alpha Psi Chapter Anniversary. Poster for College of Nursing Homecoming Celebration. East Lansing, MI.

Wyatt, G. (1996, November 19). The Breast Cancer Experience. Presentation for Unitarian Universalist Church Women's Group. East Lansing, MI.

Given, B.A., & DeVoss, D.N. (1996, November). Rural Partnership Linkage for Cancer Care Newsletter, Vol. 3, Issue 4.

Wyatt, G. (1996, Fall). INVESTIGATOR FOCUS, article featuring research by G. Wyatt. Cancer Center at Michigan State University News, East Lansing, MI.

Given, B. (1997, February 14). State Grant on Cancer Prevention, phone interview on WWJ Radio Station.

Given, C.W. (1997, February). Family Caregiving for Persons with Breast Cancer. Presented at the Cancer Center of Michigan State University Breast Cancer Support Group, East Lansing, MI.

Wyatt, G. (1997, February 18). Longer Hospital Stays Not Always the Answer. Press interview for news release through Michigan State University Division of University Relations.

Given, C.W. (1997, March 9 - 11). News interview for national distribution, Family Home Care for Cancer, conducted by Spectrum Sciences, Washington, D.C.

Lay articles and appearances, continued

Wyatt, G. (1997, March 10). Michigan State University Study to Help Women Diagnosed with Breast Cancer. Press interview for news release through Michigan State University Division of University Relations.

Wyatt, G. (1997, March 25). Mammograms Urged at Age 40. Press interview for news release through Michigan State University Division of University Relations.

Wyatt, G. & Bloomfield, M. (1997, April 11). WELG Channel 22 Cable Television. Television interview, aired twice a day April 14 through April 20, 1997.

Given, C. W. & Given, B.A., (1997, May 18). Vital Options, program interview on cancer care for radio station in Los Angeles, CA.

Breast Cancer Source Guide, Michigan State University Media Communications. (1997, June 2).

Wyatt, G. (radio interview). (1997, July 17). Nursing Care Following Short-Stay Breast Cancer Surgery. With D. Krolick, Broadcast/ Photo Division of University Relations, Michigan State University, for National 24 Hour Radio Information Hotline.

HONORS AND AWARDS

Given, C.W. (1997, February 5). Recipient of Distinguished Faculty Award. Michigan State University, East Lansing, MI.

Given, C.W. (1997, Spring). Nominated for Michigan Association Governing Boards Award, East Lansing, MI.

INTERNAL PUBLICATIONS

| | |
|---|---------------|
| Recruiter Manual, Lansing site | January 1997 |
| Nurse Intervenor Manual | February 1997 |
| Interview Manual | March 1997 |
| Recruiter Manual, Pontiac site | May 1997 |
| Patient Charting Forms | June 1997 |
| Nursing Guide to Paradox Computer Program | June 1997 |
| Quality Assurance Manual | July 1997 |

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

PROGRAM SPONSORED BY DOD GRANT
Appendix F

1997 Summer Brown Bag Presentation Series

West Fee Hall on the campus of Michigan State University

June 11, June 18, July 16, and July 23

Sponsors

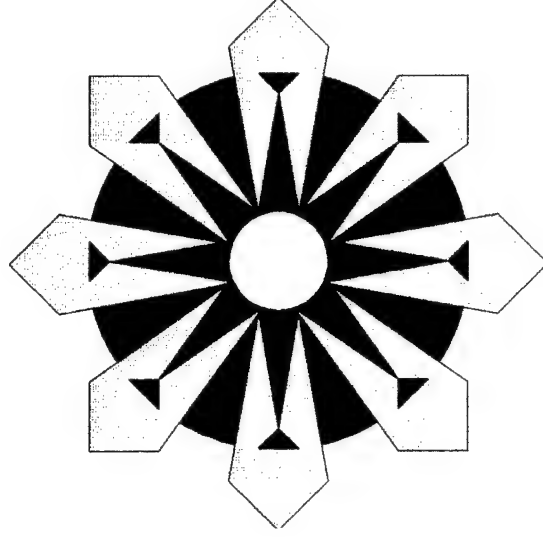
Gwen Wyatt, RN, PhD

Barbara A. Given, PhD, RN, FAAN

Charles W. Given, PhD

Supported by grant # DAMD 17-96-1-6325
U.S. Army Medical Research,
Materiel Command,
Department of Defense

1997 Summer Brown Bag Presentation Series



For more information contact:

**Kate Christensen or Mary Bloomfield
Nursing Care for Breast Cancer Study
B422 West Fee Hall
Michigan State University
East Lansing, MI 48824-1313
Phone: (517) 432-5511
Email: shrtstay@pilot.msu.edu**

Purpose

A collaborative intellectual enrichment effort for staff members of the Family Care Studies and the Nursing Care for Breast Cancer Study.

Dates and Presenters

June 11, 1997

Donna Neumark, RN, MSN

June 18, 1997

Dorothy Pathak, PhD

July 16, 1997

E.J. Siegl, MA, OCN, RN

July 23, 1997

Barbara Given, PhD, RN, FAAN

All meetings will be held in the
Managed Care Conference Room
(West Fee Hall) at 12:00pm.

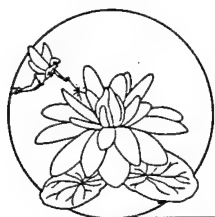
Topics

**Recruitment Issues in Research
(June 11)**

**Block Randomization
(June 18)**

**Intervention Issues in Following
Study Protocol
(July 16)**

**Building a Program of Research
&
Dissemination Issues
(July 23)**



A New Beginning

Nursing Care for Breast Cancer

B422 West Fee Hall
Michigan State University
East Lansing MI 48824-1313

Phone (517) 432-5511, Fax (517) 353-8612

June 13, 1997

Donna Neumark, RN, MSN
B-109 Clinical Center
Michigan State University
East Lansing, MI 48824

Dear Donna,

On behalf of the Nursing Care for Breast Cancer study, I'd like to extend our sincerest thanks for presenting at the 1997 Summer Brown Bag Series. We have had excellent feedback on your presentation!

Specifically, the barriers to recruitment coupled with problem solving strategies were very helpful to our staff. We also found the overheads and handouts to be useful.

Thanks for getting us off to a great start with this summer's series.

Sincerely,

Gwen Wyatt, RN, PhD



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B422 West Fee Hall
Michigan State University
East Lansing MI 48824-1313

Phone (517) 432-5511, Fax (517) 353-8612

June 20, 1997

Dorothy Pathak, PhD
B-104 Clinical Center
Michigan State University
East Lansing, MI 48824

Dear Dr. Pathak,

On behalf of the Nursing Care for Breast Cancer study, I'd like to extend our sincerest thanks for presenting at the 1997 Summer Brown Bag Series. We have had excellent feedback on your presentation!

Specifically, the factors in determining randomization for various designs were very helpful to our staff. We also found the problem solving discussion, related to current studies, interesting and insightful.

Thanks for your contribution to this summer's series.

Sincerely,

Gwen Wyatt, RN, PhD



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Michigan State University
East Lansing MI 48824-1313

Phone (517) 432-5511, Fax (517) 353-8612

July 23, 1997

E.J. Siegl, MA, OCN, RN
B-108 Clinical Center
Michigan State University
East Lansing, MI 48824

Dear E.J.,

On behalf of the Nursing Care for Breast Cancer study, I'd like to extend our sincerest thanks for presenting at the 1997 Summer Brown Bag Series. Your presentation was excellent!

Specifically, the problem solving strategies you suggested related to documentation of nursing visits were very helpful to our staff.

Thanks for your contribution to this summer's series.

Sincerely,

Gwen Wyatt, RN, PhD
Principal Investigator



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Nursing Care for Breast Cancer

B422 West Fee Hall
Michigan State University
East Lansing MI 48824-1313

Phone (517) 432-5511, Fax (517) 353-8612

July 29, 1997

Barbara Given, PhD, RN, FAAN
B-427 West Fee Hall
Michigan State University
East Lansing, MI 48824

Dear Dr. Given,

On behalf of the Nursing Care for Breast Cancer Study, we would like to extend our sincerest thanks for presenting at the 1997 Summer Brown Bag Series. Your presentation was very beneficial to our staff!

Everyone enjoyed your interactive format (and homework assignment). The discussion relating to potential research topics and dissemination of information was very helpful. Also, it would be interesting to have further discussion on developing policy statements for legislators.

Thanks so much for suggesting this summer's series and for being a presenter.

Sincerely,

Nursing Care for Breast Cancer Staff

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

STUDY BROCHURE
Appendix G

**We hope that you will decide
to participate in this
important research study**

- *We want to learn more about
how women adapt after breast
cancer surgery when they have
only a short stay in the hospital.*
 - *Participating in the study will
not change the care you will
receive from your doctors and
nurses.*
 - *Your questions are welcome.*
 - *You may choose to discontinue
your participation in the study
at any time.*
-

***Thank you for taking the time
to read about our study, and
to consider participation.***

Nursing Care for Breast Cancer

College of Nursing
B422 West Fee Hall
Michigan State University
East Lansing, Michigan 48824

*A Subacute Care Intervention for
Short-Stay Breast Cancer Surgery*

Grant number DAMD17-96-1-6325
U.S. Army Medical Research, Materiel Command,
Department of Defense

If we have already spoken to you about
our study, we may telephone you to
answer your questions and ask if you
wish to participate.

If you would like more information,

please write or phone

Dr. Gwen Wyatt, at (517) 432-5511

FAX: (517) 353-8612

e-mail: gwyatt@pilot.msu.edu



A New Beginning



A New Beginning

*Nursing Care for
Women with Breast Cancer*

Are you facing breast cancer surgery?

**Our nursing study may
provide practical help for you
in the first month after
surgery. Please read this
brochure and consider taking
part in our study.**

The purpose of this study is to assess women's progress following breast cancer surgery, with and without our nursing care visits

A woman who agrees to be a part of the study will be:

- in a group which receives their surgeons' regular care, or
- in a group which receives our nursing visits and their surgeons' regular care

A woman in the group selected for our nursing visits will receive

- help with managing after-surgery symptoms
- assistance with dressing changes and drainage care
- coaching for arm exercises and breast self-exams
- information about resources in the community


Women in the group receiving their surgeon's regular care will receive a small gift.


You are eligible for this program if you:

- ✓ are 21 years old or older
- ✓ have breast cancer
- ✓ are scheduled for breast cancer surgery
- ✓ will be discharged within 48 hours after surgery

When you give your consent to participate in the Nursing Care for Breast Cancer Study, here's what will be involved

All women in the study will

 complete a questionnaire

 participate in a telephone interview

A woman chosen to receive nursing care will receive

- two phone calls and two visits from a nurse
- regular care from her surgeon

A woman chosen to be in the control group will receive

- regular care from her surgeon
- a small gift for participating in the study

There is no cost to the women who participate in the study.

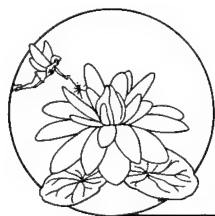
Why participate in this program?

A woman who chooses to participate in our nursing care study may have

- an opportunity to receive nursing care in her home after surgery
- counseling related to her emotional recovery
- an opportunity to help improve care for other or future breast cancer patients.

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

LETTER OF UNDERSTANDING WITH PARTICIPATING SURGEONS
Appendix H



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Michigan State University
East Lansing MI 48824-1313

Phone (517) 432-5511, Fax (517) 353-8612

SUBACUTE CARE INTERVENTION FOR SHORT-STAY BREAST CANCER SURGERY

Letter of Understanding between Collaborating Physicians and the Breast Cancer Research Project

Introduction

This project involves the participation of the Michigan State University College of Nursing and College of Human Medicine, Department of Family Practice. Women will have a 50% chance of being in the experimental arm of the study when conventional home nursing care is not ordered.

Control Group

Women in the control arm of the study will receive customary post-surgical medical care.

Experimental Group

Women in the experimental arm of the study will receive 2 phone contacts and 2 in-home visits from the study's RN, within the first two weeks after discharge for breast cancer surgery. The study nurse will report to each surgeon via summary sheets mailed to the office following each contact with the women. The surgeon will provide her/his customary post-surgical care to all women. The study nurse will contact the surgeon with any complications to the typical post-surgical healing process. The women's primary care physician will be consulted for any non-surgical health concerns.

The intervention arm of the study will consist of five areas:

- | | |
|--------------------------|-------------------------|
| 1. Assessment | 4. Resources |
| 2. Nursing Interventions | 5. Reporting to Surgeon |
| 3. Education | |

Responsibilities of the Research Nurse Providing the In-Home Intervention:

1. Contact the woman by phone within the first 24 hours after discharge for breast cancer surgery to assess for any emergent complications, schedule the first in-home visit and provide the women with the nurse's phone number.
2. Visit the woman in her home within the first 72 hours after surgical discharge.
3. During the first in-home visit, the nurse will:
 - Assess dressing, surgical site, drain, drainage, tubing
 - Assess emotional well-being and quality of life
 - take temperature and BP on opposite arm from surgical site
 - Suggest adjustment to pain medications within physician guidelines
 - Observe and support the woman with dressing change

- Observe and support the woman with emptying of drain
 - Observe and coach the woman on milking clogged tubing
 - Monitor for hematoma formation and/or inflammation at site, excessive drainage, color of skin, color of drainage
 - Support expression of feelings
 - Answer routine post-surgical questions and find answers to specific questions
 - Work with caregiver if the woman is unable to provide self-care
 - Watch for signs of infection
 - Provide information on local businesses which handle surgical dressing materials
4. Four to seven days after surgery, the nurse will make a second telephone contact with the woman to arrange the second home visit, and assess for any emergent complications.
5. During the second in-home visit, the nurse will
- Repeat all the interventions from the first visit that continue to apply
 - Observe and coach the woman as she demonstrates hand and arm exercises according to physician guidelines, or if the drain is removed, according to standard ACS guidelines
 - Observe and coach the woman as she demonstrates the Breast Self-Exam on opposite breast
 - Give ACS instructions on lymphedema prevention
 - Provide information on local support groups
 - Provide information on local businesses that sell mastectomy products and clothing
 - Offer ACS pamphlets on follow-up care (e.g., radiation, chemotherapy)
 - Offer ACS pamphlets on reconstruction/implants
6. Mail a summary of each contact to the surgeon's office
7. Consult with the surgeon for non-routine events in the healing process
8. Consult with the woman's primary care physician for any non-surgical health events

Involved parties may request in writing to revise or rescind this agreement at any time.

Please sign below:

Physician's Signature

Date

Principal Investigator's Signature

Date

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

PRE-SURGICAL INSTRUMENT
Appendix I

*A Subacute Care Intervention
for
Short-Stay Breast Cancer Surgery*

September 15, 1996 to September 14, 2000

Pre-Surgery Questionnaire

Funded by

U. S. Army Medical Research
Materiel Command
Department of Defense

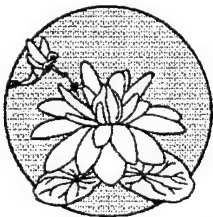
Principal Investigator:

Gwen Wyatt, RN, PhD
Associate Professor
College of Nursing

Co-principal Investigators:

Barbara Given, PhD, RN, FAAN
Professor, College of Nursing
Director of Research,
Institute of Managed Care
Associate Director, Cancer Prevention
and Control, MSU Cancer Center

Charles Given, PhD
Professor, College of Human Medicine
Associate Chair for Research
Family Practice



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East Lansing, Michigan 48824*



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Michigan State University
East Lansing MI 48824-1313

Phone (517) 432-5511, Fax (517) 353-8612

Thank you for your interest in Michigan State University's Nursing Care study. Your surgeon is among those listed below who are working with us to help learn more about how women adapt after breast cancer surgery. Please be sure you read each page of the consent form, **initial and date each page in the lower right hand corner, and sign and date the last page.** Please return the signed copy in the return-addressed stamped envelope we have enclosed for your convenience, and keep one copy for yourself.

Also included in this packet are three sets of questions that should take no longer than 15 minutes to complete. **We must receive the packet in the MSU Study Office before your surgery.** If you complete the packet while at your doctor's office, please give it to the secretary or nurse who spoke with you. If you complete the packet at home, return it along with your consent form, in the envelope provided for your use. If we have not received the packet within a few days, we will call you.

Your participation in this study is greatly appreciated. We believe that our study will offer important information to health care providers about the kind of care women need following breast cancer surgery. If you have any questions, please call our office at 517-432-5511 or toll-free at 1-888-432-5511 if you are calling long-distance.

Participating Surgeons

Dr. Keith Apelgren
Dr. Richard Dean
Dr. Rafael De Los Santos
Dr. James Harkema
Dr. Rao Kareti
Dr. John Kisala

Dr. Hugh Lindsey
Dr. Laura Morris
Dr. Janet Osuch
Dr. Carol Slomski
Dr. Ronald VanderMolen

Nursing Care for Breast Cancer Questionnaire

Directions: For questions 1 - 3, please place an "X" next to the answer you choose.

1. Do you know how to do a breast self-exam ____yes ____no
2. Do you do breast self-exams monthly? ____yes ____no
3. On which side will your breast cancer surgery be performed? ____Left ____Right ____Both
4. Circle the number above the picture that best describes the full extent you can move your **right** arm today. (If your arm movement is more than "near fully" but less than "fully", mark 4)

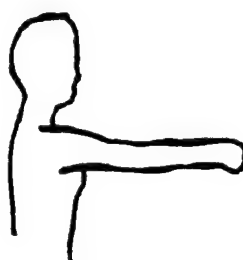
1 not at all



2 very little



3 about half



4 near fully



5 fully

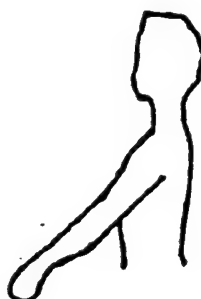


5. Circle the number above the picture that best describes the full extent you can move your **left** arm today. (If your arm movement is more than "near fully" but less than "fully," mark 4)

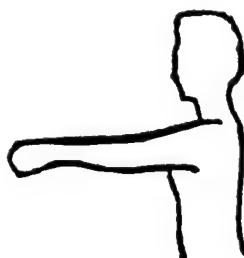
1 not at all



2 very little



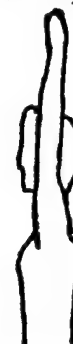
3 about half



4 near fully



5 fully



6. Are you able to pick up a nickel with your **right** hand today?

Always

Usually

Sometimes

Rarely

Unable

1

2

3

4

5

7. Are you able to pick up a nickel with your **left** hand today?

1

2

3

4

5

8. Can you touch your thumb to each finger on your **right** hand today?

1

2

3

4

5

9. Can you touch your thumb to each finger on your **left** hand today?

1

2

3

4

5

During the past 7 days:

- | | | | | |
|---------------|-----------------|---------------|----------------|--------------|
| not at all | a little bit | some- what | quite a bit | very much |
|---------------|-----------------|---------------|----------------|--------------|

(circle one number per line)

- | | | | | | | | | | |
|------------|---|---|---|---|---|---|---|---|--------------|
| Not at all | | | | | | | | | Very much so |
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 10 |

| | | | | |
|---------------|-----------------|---------------|----------------|--------------|
| not at all | a little bit | some- what | quite a bit | very much |
|---------------|-----------------|---------------|----------------|--------------|

(circle one number per line)

- | | | | | |
|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 |
| 0 | 1 | 2 | 3 | 4 |
| 0 | 1 | 2 | 3 | 4 |
| 0 | 1 | 2 | 3 | 4 |
| 0 | 1 | 2 | 3 | 4 |
| 0 | 1 | 2 | 3 | 4 |
| | | | | |
| 0 | 1 | 2 | 3 | 4 |

- Not at all Very much so
0 1 2 3 4 5 6 7 8 9 10

| | | | | |
|---------------|-----------------|---------------|----------------|--------------|
| not at all | a little bit | some- what | quite a bit | very much |
|---------------|-----------------|---------------|----------------|--------------|

(circle one number per line)

- | | | | | |
|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 |
| 0 | 1 | 2 | 3 | 4 |

- | | | | | | | | | | | |
|------------|---|--------------|---|---|---|---|---|---|---|----|
| Not at all | | Very much so | | | | | | | | |
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

(circle one number per line)

19. I feel sad.....
20. I am proud of how I'm coping with my illness.....
21. I am losing hope in the fight against my illness.....
22. I feel nervous
23. I worry about dying.....
24. I worry that my condition will get worse.....

[illegible][illegible]

(circle one number per line)

26. I am able to work (include the work in home).....
27. My work (include work in home) is fulfilling.....
28. I am able to enjoy life.....
29. I have accepted my illness.....
30. I am sleeping well.....
31. I am enjoying the things I usually do for fun.....
32. I am content with the quality of my life right now.....

[illegible]

Not at all **Very much so**

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|----|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|----|

(circle one number per line)

34. I have been short of breath.....
35. I am self-conscious about the way I dress.....
36. I feel sexually attractive.....
37. I worry about the risk of breast cancer in other family members.....
38. I worry about the effect of stress on my illness.....
39. I am bothered by a change in weight.....
40. I am able to feel like a woman.....

[illegible]

Not at all **Very much so**

0 1 2 3 4 5 6 7 8 9 10

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then mark the appropriate number to the right of the statement to indicate **how you feel right now, that is, at this moment**. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

| | not at all | some- what | moderately so | very much so |
|---|---------------|---------------|------------------|-----------------|
| 1. I feel calm..... | 1 | 2 | 3 | 4 |
| 2. I feel secure..... | 1 | 2 | 3 | 4 |
| 3. I am tense..... | 1 | 2 | 3 | 4 |
| 4. I feel strained..... | 1 | 2 | 3 | 4 |
| 5. I feel at ease..... | 1 | 2 | 3 | 4 |
| 6. I feel upset..... | 1 | 2 | 3 | 4 |
| 7. I am presently worrying over possible misfortunes..... | 1 | 2 | 3 | 4 |
| 8. I feel satisfied..... | 1 | 2 | 3 | 4 |
| 9. I feel frightened..... | 1 | 2 | 3 | 4 |
| 10. I feel comfortable..... | 1 | 2 | 3 | 4 |
| 11. I feel self-confident..... | 1 | 2 | 3 | 4 |
| 12. I feel nervous..... | 1 | 2 | 3 | 4 |
| 13. I am jittery..... | 1 | 2 | 3 | 4 |
| 14. I feel indecisive..... | 1 | 2 | 3 | 4 |
| 15. I am relaxed..... | 1 | 2 | 3 | 4 |
| 16. I feel content..... | 1 | 2 | 3 | 4 |
| 17. I am worried..... | 1 | 2 | 3 | 4 |
| 18. I feel confused..... | 1 | 2 | 3 | 4 |
| 19. I feel steady (emotionally)..... | 1 | 2 | 3 | 4 |
| 20. I feel pleasant..... | 1 | 2 | 3 | 4 |

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then mark the appropriate number to the right of the statement to indicate **how you generally feel**. There are no right or wrong answers. Do not spend much time on any one statement but give the answer which seems to describe how you generally feel.

| | almost never | some- times | often | almost always |
|---|-----------------|----------------|-------|------------------|
| 21. I feel pleasant..... | 1 | 2 | 3 | 4 |
| 22. I feel nervous and restless..... | 1 | 2 | 3 | 4 |
| 23. I feel satisfied with myself..... | 1 | 2 | 3 | 4 |
| 24. I wish I could be as happy as others seem to be..... | 1 | 2 | 3 | 4 |
| 25. I feel like a failure..... | 1 | 2 | 3 | 4 |
| 26. I feel rested..... | 1 | 2 | 3 | 4 |
| 27. I am "calm, cool, and collected"..... | 1 | 2 | 3 | 4 |
| 28. I feel that difficulties are piling up so that I cannot overcome them..... | 1 | 2 | 3 | 4 |
| 29. I worry too much over something that really doesn't matter..... | 1 | 2 | 3 | 4 |
| 30. I am happy..... | 1 | 2 | 3 | 4 |
| 31. I have disturbing thoughts..... | 1 | 2 | 3 | 4 |
| 32. I lack self-confidence..... | 1 | 2 | 3 | 4 |
| 33. I feel secure..... | 1 | 2 | 3 | 4 |
| 34. I make decisions easily..... | 1 | 2 | 3 | 4 |
| 35. I feel inadequate..... | 1 | 2 | 3 | 4 |
| 36. I am content..... | 1 | 2 | 3 | 4 |
| 37. Some unimportant thought runs through my mind and bothers me..... | 1 | 2 | 3 | 4 |
| 38. I take disappointments so keenly that I can't put them out of my mind..... | 1 | 2 | 3 | 4 |
| 39. I am a steady person (emotionally)..... | 1 | 2 | 3 | 4 |
| 40. I get in a state of tension or turmoil as I think over my recent concerns and interests..... | 1 | 2 | 3 | 4 |

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

SURGEON REPORTS

Appendix J



A New Beginning

Nursing Care for Breast Cancer

B422 West Fee Hall
Michigan State University
East Lansing MI 48824-1313

Phone (517) 432-5511, Fax (517) 353-8612

FIRST POST-OPERATIVE REPORT TO SURGEON

Dear Dr. _____,

Your patient, _____, is participating in our *Nursing Care for Breast Cancer* study. She will receive nursing care in her home for the first two weeks after her surgery at no cost.

Our home care nurse visited this patient on _____. The following areas were assessed during this visit. All areas will be covered during various visits over the two week period.

(DATE)

____ Vital signs WNL

____ Surgical healing WNL

____ Pain well controlled

____ Patient able to milk tubing and empty drain

____ No signs of infection present

____ Patient taught ROM exercises

____ Patient taught self breast exam

____ Patient taught lymphedema prevention

____ Patient adjusting emotionally to surgery and diagnosis

____ Patient given listing of community resources and support groups

Comments:

Home Care Nurse (Pat Kaelin, RN)

Pager: 517-229-8564

Phone: 517-432-5511



A New Beginning

Nursing Care for Breast Cancer

B422 West Fee Hall
Michigan State University
East Lansing MI 48824-1313

Phone (517) 432-5511, Fax (517) 353-8612

FINAL REPORT TO SURGEON

Date: _____

Dear Dr. _____:

Your patient, _____, is participating in our *Nursing Care for Breast Cancer* study. She will receive nursing care in her home for the first two weeks after her surgery at no cost.

Our home care nurse visited this patient on _____. The following areas were assessed during this visit. All areas will be covered during various visits over the two week period.

- ☐ Vital Signs WNL
- ☐ Surgical healing WNL
- ☐ Pain well controlled
- ☐ Patient able to milk tubing and empty drain
- ☐ No signs of infection present
- ☐ Patient taught ROM exercises
- ☐ Patient taught self breast exam
- ☐ Patient taught lymphedema prevention
- ☐ Patient adjusting emotionally to surgery and diagnosis
- ☐ Patient given listing of community resources and support groups
- ☐ Nursing care completed on _____. No further visits will be made. (date)

Comments: _____

Pat Kaelin, RN, Home Care Nurse
Pager: (517) 229-8564
Phone: (517) 432-5511

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

NURSE INTERVENTION AND COMPUTERIZED DOCUMENTATION
Appendix K

INTERVENTION PROTOCOL AND COMPUTERIZED DOCUMENTATION

| SESSION 1 Schedule first in-home visit. Identify emergent problems. | TYPE OF SESSION First Phone Contact | INTERVENTION OBJECTIVES | COMPUTER DOCUMENTATION |
|--|--|--|--|
| | | <p>A. Contact woman within 24 hours of discharge.</p> <p>B. Review and complete patient history (consent, demographics, allergies, comorbidities, cancer history) on computer screens or recruiter report.</p> <p>C. Establish Therapeutic Relationship</p> <ol style="list-style-type: none"> 1. Remind pt. or caregiver of study participation. Answer any questions. 2. Schedule first in-home visit. 3. Discuss how to contact nurse if problems develop and make sure woman has nurse's phone(pager) number. <p>D. Assess for emergent complications re:</p> <ol style="list-style-type: none"> 1. Symptoms (pain, nausea, etc.) 2. Incision, drain, drainage 3. Schedule same-day appointment if emergent complications are present. <p>E. Schedule first in-home visit within 72 hours after discharge if no emergent complications.</p> <p>F. See "First Home Visit" below and perform interventions as listed (or refer pt to emergency room) if an emergent complication exists. Report any emergent situation to surgeon.</p> | <p>A. Patient history screens</p> <ol style="list-style-type: none"> 1. Client Encounter Log screen: must be completed before other information can be entered into the program. Enter Intervention #1. Note: Documentation of correct intervention step or sub-step is crucial. <p>B. Client Demographics screen</p> <ol style="list-style-type: none"> 1. Ca Hx, Meds, Comorbidities screen 2. Professional relations screen (primary physician) <p>C. Complete Encounter Summary screen</p> <p>D. Emergent Complications: Arrange same day appointment (or refer pt to emergency bx) and complete the following screens as necessary:</p> <ol style="list-style-type: none"> 1. Symptom Assessment screens: pain, nausea, fatigue, fever, insomnia, diarrhea, constipation, other, and symptom status. 2. General Status screen: Include vital signs 3. Dressing & Wound Exam screen: Includes description of incision, drainage, and drain. 4. New/Ongoing Patient problems screen: enter brief SOAP note with corresponding pt problem (see "First Home Visit" below). 5. Interventions & Problem Status screen: Document interventions performed. 6. Select Reports from main menu, then Clinical Sets. Print out report and mail to surgeon. |

| SESSION 2 Assess patient's physical & emotional well-being. | TYPE OF SESSION First In-Home Visit | INTERVENTION OBJECTIVES A. Reestablish therapeutic relationship 1. Engage in brief conversation. 2. Ask how pt is doing in general. 3. Use a confident, reassuring tone of voice. B. Assess Symptoms 1. Assist patient to identify symptoms she may be experiencing 2. Assist patient to identify side effects of medications. 3. Assess level of symptom control - what is effective and non-effective 4. Discuss strategies to manage pain, nausea, fatigue, fever, insomnia, diarrhea, constipation. C. Initial Post-Surgical Assessment 1. Vital Signs 2. BP on unaffected arm 3. Assess for anomalies in vision, hearing, weight, oral intake, and skin. Teach pt about nutrition re wound healing. D. Assess Incision 1. Make sure the pt. has dressing supplies, and give pt a Drainage Chart, Incision/Drain instruction sheet, and resource list. 2. Assess and reinforce pt. skill re: dressing changes, employing the drain, measuring drainage, and stripping/milking tubing. 3. Examine incision and record location, approximation, when the dressing was last changed, and appearance/amount of drainage on the dressing. 4. Assess and teach pt about S/S infection. 5. Assess for hematoma and seroma 6. Assess closed drainage; record amount, appearance, consistency, clogs in tube. | COMPUTER DOCUMENTATION A. New Encounter Log #2 B. Complete Symptoms screens in Clinical menu: assess for pain, nausea, fatigue, fever, insomnia, diarrhea, constipation, anxiety, depression and other symptoms when applicable. Note: anxiety and depression screens are under Assessments on the Clinical Menu. C. Choose Assessment from Clinical menu. Complete General Status screen. Note: BP, Temp, Resp. are mandatory, other fields as appropriate. D. Complete Dressing & Wound Exam screen under Assessment in Clinical menu. 1. Complete Surgical Site form |
|--|--|--|--|
|--|--|--|--|

| SESSION 2 | TYPE OF SESSION | NURSING INTERVENTIONS | COMPUTER DOCUMENTATION |
|--|-----------------------------|---|--|
| Assess patient's physical & emotional well-being (cont.) | First In-Home Visit (cont.) | <p>E. Assess Anxiety</p> <ol style="list-style-type: none"> 1. Assess and document extent of anxiety. 2. Allow time for client to verbalize anxiety (do not appear to be in a hurry). 3. Identify coping strategies that have been useful for the pt in the past. 4. Teach anxiety interrupters: 1) look up, 2) Control breathing, 3) lower shoulders, 4) slow thoughts, 5) alter voice, 6) give self directions, 6) imagine watching the situation from a distance <p>F. Assess Depression</p> <ol style="list-style-type: none"> 1. Assess/document extent of depression. 2. Encourage ongoing appraisal/reappraisal about the meaning of the diagnosis: talk about feelings associated with breast cancer, impact on family members, identify sources of help. Emphasize that periods of depression and anger are normal reactions. 3. Discuss causative and contributory factors, i.e.: negative self-concept, loss-related grief, sudden change in role. 4. Promote hopefulness and realistic goal setting by employing active listening, empathy, and teaching about breast cancer and treatment modalities. 5. Reinforce the pt's self-care abilities to encourage independence and mobility, improve self-esteem, and decrease feelings of powerlessness. 6. Refer to appropriate professional or community resource if depression-related problems are beyond the scope of the nurse generalist. | <p>E. Complete Anxiety screen under Assessment in Clinical Menu (if applicable)</p> <p>F. Complete Depression screen under Assessment on Clinical Menu (if applicable)</p> |

| | | | |
|---|-------------------------------------|--|--|
| SESSION 3 Schedule 2nd In-Home Visit. Identify emergent problems | TYPE OF SESSION 2nd Phone | INTERVENTION OBJECTIVES A. Call patient 2-7 days after discharge. B. Reestablish Therapeutic Relationship 1. Remind pt. or caregiver of study. Answer any questions. 2. Schedule 2nd in-home visit. 3. Discuss how to contact nurse if problems develop and make sure patient has nurse's phone number. C. Assess for emergent complications and/or problem resolution re: 1. Symptoms (pain, nausea, etc.) 2. Incision, drain, drainage 3. Schedule same-day appointment if emergent complications are present. D. Schedule 2nd in-home visit within 72 hours after phone call. E. Perform interventions as listed for in-home visits if an emergent complication exists. Print out report for surgeon. | COMPUTER DOCUMENTATION A. Complete New Encounter Log #3 B. Document any psychosocial interventions C. Emergent Complications: Arrange same day appointment and complete the following screens as necessary: 1. Symptom Assessment: pain, nausea, fatigue, fever, insomnia, diarrhea, constipation, other, and symptom status screens. 2. General Status screen: Includes vital signs, orthostasis, etc. 3. Dressing & Wound Exam screen: Includes description of incision, drainage, and drain. D. Complete New Encounter screen E. Complete the following screens: 1. SOAP Notes and Patient Problems screen 2. Patient Problems with Interventions screen 3. Encounter Summary 4. Report - print out report for surgeon |
|---|-------------------------------------|--|--|

| SESSION 4 Assess patient's physical healing and emotional well-being. Teach Breast Self-Exam, ROM exercises and lymphedema prevention. | TYPE OF SESSION 2nd In-Home Visit | INTERVENTION OBJECTIVES A. Reestablish therapeutic relationship 1. Greet pt. in a pleasant manner 2. Ask how pt is doing in general 3. Use a confident, reassuring tone of voice B. Assess Symptoms: 1. Assist patient to identify symptoms she may be experiencing 2. Assist patient to identify side effects of medications. 3. Assess level of symptom control - what is effective and non-effective. 4. Discuss strategies to manage pain, nausea, fatigue, fever, insomnia, diarrhea, constipation. C. Second Post-Surgical Assessment 1. Vital signs 2. BP on unaffected arm. 3. Assess for anomalies in vision, hearing, weight, oral intake, and skin. Teach pt about nutrition re wound healing. D. Assess Incision 1. Make sure pt. has dressing supplies. 2. Assess and reinforce pt. skill re: dressing changes, emptying the drain, measuring drainage, and stripping/milking tubing. 3. Examine incision and record location, approximation, when the dressing was last changed, and appearance/amount of drainage on the dressing. 4. Assess and teach pt about S/S infection. 5. Assess for hematoma and seroma. 6. Assess closed drainage: record amount, appearance and consistency. 7. Assess for clogs in the tubing. | COMPUTER DOCUMENTATION A. New Encounter Log #4 B. Complete Symptom Assessment screens: Includes pain, nausea, fatigue, fever, insomnia, diarrhea, constipation, and other symptoms if applicable: 1. Document symptom management/monitoring on New/Ongoing Pt. Problems screen. 2. Document interventions on Interventions and problem Status screen 3. Complete Referral screen if appropriate. Enter separate encounter log for each referral initiated. 4. Complete New/Ongoing Patient Problems screen and Interventions and Problem Status. C. Complete General Status screen D. Complete Dressing & Wound Exam screen |
|--|--------------------------------------|--|---|
|--|--------------------------------------|--|---|

| SESSION 4 | TYPE OF SESSION | INTERVENTION OBJECTIVES | COMPUTER DOCUMENTATION |
|--|----------------------------------|--|---|
| <p>Assess woman's physical healing and emotional well-being.</p> <p>Teach Breast Self-Exam, ROM exercises and lymphedema prevention.</p> | <p>2nd In-Home Visit (cont.)</p> | <p>E. Facilitate early detection of breast cancer.</p> <ol style="list-style-type: none"> 1. Teach Breast Self-Exam, shower method: 1) Check monthly one week after period or on first day of the month. 2) Keep fingers flat while moving gently over every part of the breast. 3) Use right hand to examine left breast, left hand for right breast. 4) Check for lumps, knots, thickening. 2. Provide guide to use in the shower 3. Emphasize the need to examine tail of spence. <p>F. Minimize/Prevent Lymphedema</p> <ol style="list-style-type: none"> 1. Teach pt. about effects of lymph node removal: 1) drainage of lymph fluid may be slowed and 2) ability to fight infection may be impaired. 2. Teach pt. to avoid burns and breaks in skin of affected arm/hand: 1) use gloves, thimble, lotion, electric razor. Avoid blood draws on affected arm. 3. Teach pt. to avoid squeezing pressure to arm and hand: 1) avoid BP on affected arm, 2) avoid elastic sleeves and tight jewelry, 3) carry heavy articles with unaffected arm. 4. Teach pt. to elevate arm when sitting or lying. If arm begins to swell: 1) position arm with wrist above elbow, 2) squeeze/unsqueeze fist to reabsorb fluid. 5. Encourage pt. to gradually increase movement in affected arm. 6. Explain that tightness/tingling should diminish with time & gradual exercise. | <p>E. Self Exam and Lymphedema screen (Self Breast Exam portion)</p> <p>F. Self-Exam and Lymphedema screen (Lymphedema portion)</p> |

| SESSION 4 Assess woman's healing and emotional well-being. Teach Breast Self-Exam, ROM exercises, and Lymphedema prevention. | TYPE OF SESSION 2nd In-Home (cont.) | INTERVENTION 7. Assess phantom breast sensation. 8. Explain that phantom breast sensation is not abnormal, and that it may or may not subside with time. G. Assess ROM, fine motor ability, and sensation in affected arm and chest wall. 1. Begin light ADL's according to surgeon guidelines, and encourage pt. to gradually increase arm activity. 2. Assess ROM and teach ROM exercises according to surgeon guidelines. General guidelines (see ROM Guidelines) include hand-wall climbing, back scratcher, arm swing, elbow pull-in. 3. Use pain medication as needed to allow exercise without pain hindrance. 4. Look for signs of nerve and/or circulation impairment in affected arm. 5. Assess tightness in chest wall. 6. Assess affected hand fine motor ability. H. Assess Anxiety 1. Assess and document extent of anxiety. 2. Allow time for client to verbalize anxiety (do not appear to be in a hurry). 3. Identify coping strategies that have been useful for the pt in the past. 4. Teach anxiety interrupters: 1) look up, 2) Control breathing, 3) lower shoulders, 4) slow thoughts, 5) alter voice, 6) give self directions, 6) imagine watching the situation from a distance. | COMPUTER DOCUMENTATION G. Complete Recovery screen H. Complete Anxiety screen |
|--|--|--|---|
|--|--|--|---|

| | | | |
|---|---|--|---|
| <p>SESSION 4</p> <p>Assess woman's physical healing and emotional well-being. Teach Breast Self-Exam, ROM exercises and lymphedema prevention.</p> | <p>TYPE OF SESSION 2nd In-Home Visit (cont.)</p> | <p>INTERVENTION OBJECTIVES</p> <p>I. Assess Depression</p> <ol style="list-style-type: none"> 1. Assess/document extent of depression. 2. Encourage ongoing appraisal/reappraisal about the meaning of the diagnosis: talk about feelings associated with breast cancer, impact on family members, identify sources of help. Emphasize that periods of depression and anger are normal reactions. 3. Discuss causative and contributory factors, i.e.: negative self-concept, loss-related grief, sudden change in role. 4. Promote hopefulness and realistic goal setting by employing active listening, empathy, and teaching about breast cancer and treatment modalities. 5. Reinforce the pt's self-care abilities to encourage independence and mobility, improve self-esteem, and decrease feelings of powerlessness. 6. Refer to appropriate professional or community resource if depression-related problems are beyond the scope of the nurse generalist. <p>J. Refer woman to appropriate service professional if problems are beyond the scope of the nurse generalist (social worker, etc.)</p> <ol style="list-style-type: none"> 1. Explore what services the woman's insurance will cover. 2. Encourage woman to contact her primary care physician for additional services. | <p>COMPUTER DOCUMENTATION</p> <p>I. Complete Depression screen</p> <p>J. Patient Service Referral screen (fill in as many as needed)</p> |
|---|---|--|---|

| | | | |
|--|---|--|---|
| <p>SESSION 4</p> <p>Assess woman's physical healing and emotional well-being. Teach Breast Self-Exam, ROM exercises and lymphedema prevention</p> | <p>TYPE OF SESSION</p> <p>2nd In-Home (cont.).</p> | <p>INTERVENTION OBJECTIVES</p> <p>K. Refer woman to community resources as needed (American Cancer Society, etc.)</p> <ol style="list-style-type: none"> 1. Provide pt. with packet of printed information. 2. Explore the woman's needs and refer to appropriate community resources. <p>L. Thank woman for participating in study, and inform her that this is the last visit. Refer woman to primary physician for further treatment.</p> <p>M. Complete documentation and print out report for surgeon.</p> | <p>COMPUTER DOCUMENTATION</p> <p>K. Patient Service Referral screen (fill in as many as needed)</p> <p>L. No Documentation</p> <p>M. SOAP notes and Patient Problems screen</p> <ol style="list-style-type: none"> 1. Patient Problems with Interventions screen 2. Encounter Summary screen 3. Patient Summary screen 3. Select Report and print out Report for surgeon |
|--|---|--|---|

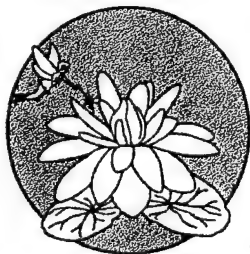
A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

NURSE CHARTING FORM
Appendix L

Nursing Care for Breast Cancer Nurse Charting Form

| Topic | Page |
|---|-------------|
| Charting diagram | A |
| Essential Problems & Interventions . | 1 |
| List of visits (Encounter Log) | 2 |
| Cancer history, meds, comorbidities ... | 3 |
| Symptoms | |
| Overview | 4 |
| Pain | 5 |
| Nausea | 6 |
| Fatigue | 7 |
| Fever | 8 |
| Insomnia | 9 |
| Diarrhea | 10 |
| Constipation | 11 |
| Other | 12 |
| Assessments | |
| General status | 13 |
| Dressing & wound exam | 14 |
| Surgical sites chart | 15 |
| BSE & lymphedema | 16 |
| Sensation & fine motor | 17 |
| Quality of life | 17 |
| Anxiety | 18 |
| Depression | 19 |
| New/ongoing patient problems | |
| Encounters 1,2,3,4 | 20 |
| Other problems | 21 |

| Topic | Page |
|----------------------------------|-------------|
| Interventions & problem status | |
| Encounter 1 | 22 |
| Encounter 2 | |
| Constipation | 23 |
| Pain | 23 |
| Activity intolerance | 24 |
| Quality of life | 24 |
| Know. deficit, milk drain .. | 25 |
| Know. deficit, empty drain .. | 25 |
| Know. def., record drainage .. | 26 |
| Consultation, rept. to dr ... | 26 |
| Encounter 3 | 27 |
| Encounter 4 | |
| Constipation | 28 |
| Pain | 28 |
| Activity intolerance | 29 |
| Quality of life | 29 |
| Skin integrity | 30 |
| Know. deficit, dress. chng .. | 30 |
| Know. deficit, milk drain .. | 31 |
| Know. deficit, empty drain .. | 31 |
| Know. def., record drainage .. | 32 |
| Know. def., lymphedema .. | 32 |
| Know. deficit, BSE | 33 |
| Know. deficit, ROM | 33 |
| Consultation, final care rept .. | 34 |
| Other problems | 35 |
| Encounter screen | 36 |
| Referrals | 37 |
| Physician consultations | 38 |
| Summaries | 39 |



....A New Beginning

Nurse Intervener Charting

LOG ENCOUNTER

List of Visits by Patient

CLINICAL

Cancer History, Medications, Comorbid

(finish gathering information)

1. Allergies
2. Medications
3. Comorbid

Symptoms

- | | | |
|------------|-------------|-----------------|
| 1. Pain | 4. Fever | 7. Constipation |
| 2. Nausea | 5. Insomnia | 8. Other |
| 3. Fatigue | 6. Diarrhea | |

Assessment

- | | |
|------------------------------|--------------------|
| 1. General Status (Physical) | 5. Quality of Life |
| 2. DRG and Wound Exam | 6. Anxiety |
| 3. BSE and Lymphedema | 7. Depression |
| 4. Sensation and Fine Motor | |

New/Ongoing Patient Problems

1. SOAP
2. ICD Problem Lists

Intervention and Problem Status

1. Problem and Status
2. Interventions

Encounter Screen

1. CPT (primary) Level of Care
2. Time per Visit and Recording

Referrals

1. Patient Service Referrals

Summaries

1. General Summary per Patient at Last Encounter Only
2. Nurse Information

Essential Protocol Problems and Interventions

VISIT 1 (Intervention Step 2.0)

| <i>Problem</i> | <i>Problem Code</i> | <i>ICD</i> | <i>Intervention</i> |
|--|---------------------|------------|--|
| Constipation Constipation | 1580 | 564.0 | Constipation ASSES _1460 Medications TEACH _2850 OTC medications PRESC _3120 |
| Pain Pain, acute | 2380 | 611.71 | Pain control ASSES _3140 Medication TEACH _2850 |
| Fatigue Activity intolerance (physical) | 1020 | 780.7 | Fatigue ASSES _2000 Sleep/rest hygiene TEACH _3638 |
| Anxiety Anxiety | 1080 | 309.24 | Anxiety ASSES _1090 Anxiety management TEACH _1115 |
| Quality of life Alter. QOL | 2479 | V62.89 | Quality of life ASSES _3381 Support re individ. COUNS _3694 Give ed. materials TEACH _2220 |
| Incision Knowledge deficit, milking drain | 2144 | V62.3 | Milking drainage tube - patient TEACH _3214 |
| Knowledge deficit, empty drain | 2162 | V62.3 | Empty drain - patient TEACH _3213 |
| Knowledge deficit, recording drainage | 2185 | V62.3 | Recording drainage - patient TEACH _3216 |
| Consultation Consultation, rept. to dr. | 1585 | V65.8 | Week 1 care report - surgeon REPORT _8050 |

Essential Protocol Problems and Interventions

VISIT 2 (Intervention Step 4)

| <i>Problem</i> | <i>Problem Code</i> | <i>ICD</i> | <i>Intervention</i> |
|---|---------------------|------------|---|
| Constipation | | | |
| Constipation | 1580 | 564.0 | Constipation EVAL _1470 |
| Pain | | | |
| Pain, acute | 2380 | 611.71 | OTC medications ... PRESC _3120 Pain control EVAL _3150 |
| Fatigue | | | |
| Activity intolerance | 1020 | 780.7 | Fatigue EVAL _2010 |
| Anxiety | | | |
| Anxiety | 1080 | 309.24 | Anxiety EVAL _1110 |
| Quality of life | | | |
| Alter. in QOL | 2479 | V62.89 | Quality of life EVAL _3382 Support group REFER _5355 |
| Incision | | | |
| Skin integrity/surgery (open new problem, if not already open) | 2675 | 879.0 | Assess - wound ASSES _3630 Skin care - wound .. TEACH _3580 Give ed. materials .. TEACH _2220 Infection control ... TEACH _2540 Incision care EVAL _2490 |
| Knowledge def., drsg. change (open new problem, if not already open) | 2164 | V62.3 | Dressing change SKILL _1760 Dressing change - pt TEACH _3211 Dressing change EVAL _1745 |
| Knowledge def., milk drain | 2144 | V62.3 | Milk drainage tube ... EVAL _1735 |
| Knowledge def., empty drain | 2162 | V62.3 | Emptying drain EVAL _1733 |
| Knowledge def., rec. drainage | 2185 | V62.3 | Recording drainage .. EVAL _1738 |
| Education (open as new problems) | | | |
| Knowledge def., lymphedema | 2224 | V62.3 | Lymphedema prev. . TEACH _2725 Give education mat. . TEACH _2220 Lymphedema know. . EVAL _2727 |
| Knowledge def., BSE | 2155 | V62.3 | Self breast exam ... TEACH _1207 Give ed. Materials . TEACH _2220 Self breast exam EVAL _1204 |
| Knowledge def., ROM - effected arm | 2146 | V62.3 | ROM arm DEMO _9020 Exercise/ROM TEACH _1870 Give ed materials .. TEACH _2220 Exercise/ROM EVAL _1840 Functional level (arm) EVAL _2190 |
| Consultation | | | |
| Consultation, report to doctor | 1585 | V65.8 | Final care report to surgeon REPORT _8000 |

CLIENT ENCOUNTER LOG

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

Encounter timing: ☐ Phone 1 ☐ Phone 2 ☐ Visit 1 ☐ Visit 2
☐ Between intervention phone ☐ Between intervention visit
☐ Post intervention phone ☐ Post intervention visit

Encounter type: ☐ Client phoned ☐ Nurse phoned ☐ Nurse visited client at home
☐ Nurse spoke to MD ☐ Nurse spoke with other ☐ Family phoned nurse

Interven. Step #: 1, 2, 3, 4 - Use no. with decimal point for between intervention contacts, eg., 1.1 _____

Encounter purpose: ☐ Scheduled part of interven. ☐ Follow-up with pt ☐ Planning for pt on pt behalf
☐ Referral ☐ Reschedule appt. ☐ Unschedule appt. ☐ Coordination of services

Memo: _____

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

Encounter timing: ☐ Phone 1 ☐ Phone 2 ☐ Visit 1 ☐ Visit 2
☐ Between intervention phone ☐ Between intervention visit
☐ Post intervention phone ☐ Post intervention visit

Encounter type: ☐ Client phoned ☐ Nurse phoned ☐ Nurse visited client at home
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Interven. Step #: 1, 2, 3, 4 - Use no. with decimal point for between intervention contacts, eg., 1.1 _____

Encounter purpose: ☐ Scheduled part of interven. ☐ Follow-up with pt ☐ Planning for pt on pt behalf
☐ Referral ☐ Reschedule appt. ☐ Unschedule appt. ☐ Coordination of services

Memo: _____

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

Encounter timing: ☐ Phone 1 ☐ Phone 2 ☐ Visit 1 ☐ Visit 2
☐ Between intervention phone ☐ Between intervention visit
☐ Post intervention phone ☐ Post intervention visit

Encounter type: ☐ Client phoned ☐ Nurse phoned ☐ Nurse visited client at home
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Interven. Step #: 1, 2, 3, 4 - Use no. with decimal point for between intervention contacts, eg., 1.1 _____

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☐ Referral ☐ Reschedule appt. ☐ Unschedule appt. ☐ Coordination of services

Memo: _____

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

Encounter timing: ☐ Phone 1 ☐ Phone 2 ☐ Visit 1 ☐ Visit 2
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Encounter type: ☐ Client phoned ☐ Nurse phoned ☐ Nurse visited client at home
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Encounter purpose: ☐ Scheduled part of interven. ☐ Follow-up with pt ☐ Planning for pt on pt behalf
☐ Referral ☐ Reschedule appt. ☐ Unschedule appt. ☐ Coordination of services

Memo: _____

CLIENT ENCOUNTER LOG

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

Encounter timing: ☐ Phone 1 ☐ Phone 2 ☐ Visit 1 ☐ Visit 2
☐ Between intervention phone ☐ Between intervention visit
☐ Post intervention phone ☐ Post intervention visit

Encounter type: ☐ Client phoned ☐ Nurse phoned ☐ Nurse visited client at home
☐ Nurse spoke to MD ☐ Nurse spoke with other ☐ Family phoned nurse

Interven. Step #: 1, 2, 3, 4 - Use no. with decimal point for between intervention contacts, eg., 1.1 _____

Encounter purpose: ☐ Scheduled part of interven. ☐ Follow-up with pt ☐ Planning for pt on pt behalf
☐ Referral ☐ Reschedule appt. ☐ Unschedule appt. ☐ Coordination of services

Memo: _____

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

Encounter timing: ☐ Phone 1 ☐ Phone 2 ☐ Visit 1 ☐ Visit 2
☐ Between intervention phone ☐ Between intervention visit
☐ Post intervention phone ☐ Post intervention visit

Encounter type: ☐ Client phoned ☐ Nurse phoned ☐ Nurse visited client at home
☐ Nurse spoke to MD ☐ Nurse spoke with other ☐ Family phoned nurse

Interven. Step #: 1, 2, 3, 4 - Use no. with decimal point for between intervention contacts, eg., 1.1 _____

Encounter purpose: ☐ Scheduled part of interven. ☐ Follow-up with pt ☐ Planning for pt on pt behalf
☐ Referral ☐ Reschedule appt. ☐ Unschedule appt. ☐ Coordination of services

Memo: _____

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

Encounter timing: ☐ Phone 1 ☐ Phone 2 ☐ Visit 1 ☐ Visit 2
☐ Between intervention phone ☐ Between intervention visit
☐ Post intervention phone ☐ Post intervention visit

Encounter type: ☐ Client phoned ☐ Nurse phoned ☐ Nurse visited client at home
☐ Nurse spoke to MD ☐ Nurse spoke with other ☐ Family phoned nurse

Interven. Step #: 1, 2, 3, 4 - Use no. with decimal point for between intervention contacts, eg., 1.1 _____

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☐ Referral ☐ Reschedule appt. ☐ Unschedule appt. ☐ Coordination of services

Memo: _____

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

Encounter timing: ☐ Phone 1 ☐ Phone 2 ☐ Visit 1 ☐ Visit 2
☐ Between intervention phone ☐ Between intervention visit
☐ Post intervention phone ☐ Post intervention visit

Encounter type: ☐ Client phoned ☐ Nurse phoned ☐ Nurse visited client at home
☐ Nurse spoke to MD ☐ Nurse spoke with other ☐ Family phoned nurse

Interven. Step #: 1, 2, 3, 4 - Use no. with decimal point for between intervention contacts, eg., 1.1 _____

Encounter purpose: ☐ Scheduled part of interven. ☐ Follow-up with pt ☐ Planning for pt on pt behalf
☐ Referral ☐ Reschedule appt. ☐ Unschedule appt. ☐ Coordination of services

Memo: _____

Cancer History, Medications, Comorbids

Patient Name _____ ID# _____

Dates of Visits: _____ Visit 1 _____ Visit 2 _____ Visit 3 _____ Visit 4 _____ Visit 5

Hormone Replacement Therapy: ☐ YES (Note on final surgeon report -- "RE-EVALUATE") ☐ NO

Allergies: _____

| MEDICATIONS | |
|-------------|-----|
| 1. | 6. |
| 2. | 7. |
| 3. | 8. |
| 4. | 9. |
| 5. | 10. |

| COMORBIDS (please match medications, by number, with their corresponding comorbids) | | | | |
|---|------------|----------------------------|---|-----------------|
| Comorbids | Date Began | Limiting (1 to 5 scale) | Change since last visit (-2 to +3 scale) | Today's date |
| 1. | | | | |
| 2. | | | | |
| 3. | | | | |
| 4. | | | | |
| 5. | | | | |
| 6. | | | | |
| 7. | | | | |
| 8. | | | | |
| 9. | | | | |
| 10. | | | | |

Limiting Scale:

1= no extent at all
2= a small extent
3= some extent
4= a great extent
5= very great extent

Comorbid Change Scale:

-2= much worse since last visit
-1= somewhat worse
0= about the same
+1= somewhat better
+2= much better
+3= resolved/cleared up

SYMPTOM STATUS FOR THIS ENCOUNTER

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

Choices are: **FILL IN (FI)** - Symptom is new or changed - fill in the screen
NO PROB (NP) - No data to report - Symptom is NOT present
AS LAST (AL) - Symptom(s) status is EXACTLY as last assessed

Complete all entries then enter the appropriate symptom panels

Pain _____ Nausea _____ Fatigue _____ Fever _____
Insomnia _____ Diarrhea _____ Constipation _____ Other _____

Depression and Anxiety are entered under the menu option for Assessments

Depression _____ Anxiety _____

Date ____/____/____ Log # _____ Encounter # _____

Choices are: **FILL IN (FI)** - Symptom is new or changed - fill in the screen
NO PROB (NP) - No data to report - Symptom is NOT present
AS LAST (AL) - Symptom(s) status is EXACTLY as last assessed

Complete all entries then enter the appropriate symptom panels

Pain _____ Nausea _____ Fatigue _____ Fever _____
Insomnia _____ Diarrhea _____ Constipation _____ Other _____

Depression and Anxiety are entered under the menu option for Assessments

Depression _____ Anxiety _____

Date ____/____/____ Log # _____ Encounter # _____

Choices are: **FILL IN (FI)** - Symptom is new or changed - fill in the screen
NO PROB (NP) - No data to report - Symptom is NOT present
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Complete all entries then enter the appropriate symptom panels

Pain _____ Nausea _____ Fatigue _____ Fever _____
Insomnia _____ Diarrhea _____ Constipation _____ Other _____

Depression and Anxiety are entered under the menu option for Assessments

Depression _____ Anxiety _____

Date ____/____/____ Log # _____ Encounter # _____

Choices are: **FILL IN (FI)** - Symptom is new or changed - fill in the screen
NO PROB (NP) - No data to report - Symptom is NOT present
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Complete all entries then enter the appropriate symptom panels

Pain _____ Nausea _____ Fatigue _____ Fever _____
Insomnia _____ Diarrhea _____ Constipation _____ Other _____

Depression and Anxiety are entered under the menu option for Assessments

Depression _____ Anxiety _____

SYMPTOM STATUS FOR THIS ENCOUNTER

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

Choices are: **FILL IN (FI)** - Symptom is new or changed - fill in the screen
NO PROB (NP) - No data to report - Symptom is NOT present
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Complete all entries then enter the appropriate symptom panels

Pain _____ Nausea _____ Fatigue _____ Fever _____
Insomnia _____ Diarrhea _____ Constipation _____ Other _____

Depression and Anxiety are entered under the menu option for Assessments

Depression _____ Anxiety _____

Date ____/____/____ Log # _____ Encounter # _____

Choices are: **FILL IN (FI)** - Symptom is new or changed - fill in the screen
NO PROB (NP) - No data to report - Symptom is NOT present
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Complete all entries then enter the appropriate symptom panels

Pain _____ Nausea _____ Fatigue _____ Fever _____
Insomnia _____ Diarrhea _____ Constipation _____ Other _____

Depression and Anxiety are entered under the menu option for Assessments

Depression _____ Anxiety _____

Date ____/____/____ Log # _____ Encounter # _____

Choices are: **FILL IN (FI)** - Symptom is new or changed - fill in the screen
NO PROB (NP) - No data to report - Symptom is NOT present
AS LAST (AL) - Symptom(s) status is EXACTLY as last assessed

Complete all entries then enter the appropriate symptom panels

Pain _____ Nausea _____ Fatigue _____ Fever _____
Insomnia _____ Diarrhea _____ Constipation _____ Other _____

Depression and Anxiety are entered under the menu option for Assessments

Depression _____ Anxiety _____

Date ____/____/____ Log # _____ Encounter # _____

Choices are: **FILL IN (FI)** - Symptom is new or changed - fill in the screen
NO PROB (NP) - No data to report - Symptom is NOT present
AS LAST (AL) - Symptom(s) status is EXACTLY as last assessed

Complete all entries then enter the appropriate symptom panels

Pain _____ Nausea _____ Fatigue _____ Fever _____
Insomnia _____ Diarrhea _____ Constipation _____ Other _____

Depression and Anxiety are entered under the menu option for Assessments

Depression _____ Anxiety _____

SYMPTOMS

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

PAIN: Date Began ____/____/____ Location: _____ Radiated to: _____
 Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned
 Quality (check one): ☐ WNL ☐ cramping ☐ dull ☐ sharp-stab ☐ burning
 ☐ aching ☐ throbbing ☐ tender ☐ breakthrough pain
 Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____
 Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____ emotions _____
 relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____
Prescriptive relief: _____ **Non-Prescriptive relief:** _____
 Cause: ☐ activity ☐ disease process ☐ surgery ☐ meds ☐ unknown
 Associated symptoms: ☐ agitation ☐ altered cognition ☐ anxiety ☐ constipation
 ☐ diaphoresis ☐ dizziness ☐ dyspnea ☐ fatigue ☐ insomnia ☐ irritability
 ☐ loss of concentration ☐ muscle tension ☐ nausea ☐ palpitation ☐ sex disturbance
 Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened
 Date ended: _____ Note: _____

Date ____/____/____ Log # _____ Encounter # _____

PAIN: Date Began: _____ Location: _____ Radiated to: _____
 Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned
 Quality (check one): ☐ WNL ☐ cramping ☐ dull ☐ sharp-stab ☐ burning
 ☐ aching ☐ throbbing ☐ tender ☐ breakthrough pain
 Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____
 Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____ emotions _____
 relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____
Prescriptive relief: _____ **Non-Prescriptive relief:** _____
 Cause: ☐ activity ☐ disease process ☐ surgery ☐ meds ☐ unknown
 Associated symptoms: ☐ agitation ☐ altered cognition ☐ anxiety ☐ constipation ☐ diaphoresis
 ☐ dizziness ☐ dyspnea ☐ fatigue ☐ insomnia ☐ irritability
 ☐ loss of concentration ☐ muscle tension ☐ nausea ☐ palpitation ☐ sex disturbance
 Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened
 Date ended: _____ Note: _____

Date ____/____/____ Log # _____ Encounter # _____

PAIN: Date Began: _____ Location: _____ Radiated to: _____
 Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned
 Quality (check one): ☐ WNL ☐ cramping ☐ dull ☐ sharp-stab ☐ burning
 ☐ aching ☐ throbbing ☐ tender ☐ breakthrough pain
 Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____
 Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____ emotions _____
 relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____
Prescriptive relief: _____ **Non-Prescriptive relief:** _____
 Cause: ☐ activity ☐ disease process ☐ surgery ☐ meds ☐ unknown
 Associated symptoms: ☐ agitation ☐ altered cognition ☐ anxiety ☐ constipation ☐ diaphoresis
 ☐ dizziness ☐ dyspnea ☐ fatigue ☐ insomnia ☐ irritability
 ☐ loss of concentration ☐ muscle tension ☐ nausea ☐ palpitation ☐ sex disturbance
 Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened
 Date ended: _____ Note: _____

SYMPTOMS

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

PAIN: Date Began ____/____/____ Location: _____ Radiated to: _____
 Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned
 Quality (check one): ☐ WNL ☐ cramping ☐ dull ☐ sharp-stab ☐ burning
 ☐ aching ☐ throbbing ☐ tender ☐ breakthrough pain
 Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____
 Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____ emotions _____
 relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____
 Prescriptive relief: _____ Non-Prescriptive relief: _____
 Cause: ☐ activity ☐ disease process ☐ surgery ☐ meds ☐ unknown
 Associated symptoms: ☐ agitation ☐ altered cognition ☐ anxiety ☐ constipation
 ☐ diaphoresis ☐ dizziness ☐ dyspnea ☐ fatigue ☐ insomnia ☐ irritability
 ☐ loss of concentration ☐ muscle tension ☐ nausea ☐ palpitation ☐ sex disturbance
 Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened
 Date ended: _____ Note: _____

Date ____/____/____ Log # _____ Encounter # _____

PAIN: Date Began: _____ Location: _____ Radiated to: _____
 Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned
 Quality (check one): ☐ WNL ☐ cramping ☐ dull ☐ sharp-stab ☐ burning
 ☐ aching ☐ throbbing ☐ tender ☐ breakthrough pain
 Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____
 Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____ emotions _____
 relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____
 Prescriptive relief: _____ Non-Prescriptive relief: _____
 Cause: ☐ activity ☐ disease process ☐ surgery ☐ meds ☐ unknown
 Associated symptoms: ☐ agitation ☐ altered cognition ☐ anxiety ☐ constipation ☐ diaphoresis
 ☐ dizziness ☐ dyspnea ☐ fatigue ☐ insomnia ☐ irritability
 ☐ loss of concentration ☐ muscle tension ☐ nausea ☐ palpitation ☐ sex disturbance
 Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened
 Date ended: _____ Note: _____

Date ____/____/____ Log # _____ Encounter # _____

PAIN: Date Began: _____ Location: _____ Radiated to: _____
 Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned
 Quality (check one): ☐ WNL ☐ cramping ☐ dull ☐ sharp-stab ☐ burning
 ☐ aching ☐ throbbing ☐ tender ☐ breakthrough pain
 Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____
 Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____ emotions _____
 relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____
 Prescriptive relief: _____ Non-Prescriptive relief: _____
 Cause: ☐ activity ☐ disease process ☐ surgery ☐ meds ☐ unknown
 Associated symptoms: ☐ agitation ☐ altered cognition ☐ anxiety ☐ constipation ☐ diaphoresis
 ☐ dizziness ☐ dyspnea ☐ fatigue ☐ insomnia ☐ irritability
 ☐ loss of concentration ☐ muscle tension ☐ nausea ☐ palpitation ☐ sex disturbance
 Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened
 Date ended: _____ Note: _____

SYMPTOMS

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

NAUSEA: Date began: ____/____/____ #Emesis/Day ____ Can't retain (check one) Liquids ____ Solids ____
 Intensity (1-10 scale): ____ Max in last 7 days: ____ Tolerable level: ____
 Extent symptom interferes with (1-10 scale): sleep ____ appetite ____ mobility ____
 emotions ____ relationships ____ usual daily activity ____ ability to concentrate ____ QOL ____
Prescriptive relief: **Non-Prescriptive relief:**
 Cause: ☐ activity ☐ disease process ☐ eating ☐ odor ☐ pain
☐ emotions ☐ surgery ☐ treatment/meds ☐ unknown ____
Associated Symptoms: ☐ sweating ☐ palpitation ☐ dyspnea ☐ pain ☐ vomiting
☐ dizziness ☐ irritability ☐ depression ☐ anxiety ☐ fatigue
Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened
 Date ended: ____
 Note _____

Date ____/____/____ Log # _____ Encounter # _____

NAUSEA: Date began: ____ #Emesis/Day ____ Can't retain (check one) Liquids ____ Solids ____
 Intensity (1-10 scale): ____ Max in last 7 days: ____ Tolerable level: ____
 Extent symptom interferes with (1-10 scale): sleep ____ appetite ____ mobility ____
 emotions ____ relationships ____ usual daily activity ____ ability to concentrate ____ QOL ____
Prescriptive relief: **Non-Prescriptive relief:**
 Cause: ☐ activity ☐ disease process ☐ eating ☐ odor ☐ pain
☐ emotions ☐ surgery ☐ treatment/meds ☐ unknown ____
Associated Symptoms: ☐ sweating ☐ palpitation ☐ dyspnea ☐ pain ☐ vomiting
☐ dizziness ☐ irritability ☐ depression ☐ anxiety ☐ fatigue
Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened
 Date ended: ____
 Note _____

Date ____/____/____ Log # _____ Encounter # _____

NAUSEA: Date began: ____ #Emesis/Day ____ Can't retain (check one) Liquids ____ Solids ____
 Intensity (1-10 scale): ____ Max in last 7 days: ____ Tolerable level: ____
 Extent symptom interferes with (1-10 scale): sleep ____ appetite ____ mobility ____
 emotions ____ relationships ____ usual daily activity ____ ability to concentrate ____ QOL ____
Prescriptive relief: **Non-Prescriptive relief:**
 Cause: ☐ activity ☐ disease process ☐ eating ☐ odor ☐ pain
☐ emotions ☐ surgery ☐ treatment/meds ☐ unknown ____
Associated Symptoms: ☐ sweating ☐ palpitation ☐ dyspnea ☐ pain ☐ vomiting
☐ dizziness ☐ irritability ☐ depression ☐ anxiety ☐ fatigue
Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened
 Date ended: ____ Note _____

SYMPTOMS

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

NAUSEA: Date began: ____/____/____ #Emesis/Day ____ Can't retain (check one) Liquids ____ Solids ____

Intensity (1-10 scale): ____ Max in last 7 days: ____ Tolerable level: ____

Extent symptom interferes with (1-10 scale): sleep ____ appetite ____ mobility ____
emotions ____ relationships ____ usual daily activity ____ ability to concentrate ____ QOL ____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ activity ☐ disease process ☐ eating ☐ odor ☐ pain
☐ emotions ☐ surgery ☐ treatment/meds ☐ unknown

Associated Symptoms: ☐ sweating ☐ palpitation ☐ dyspnea ☐ pain ☐ vomiting
☐ dizziness ☐ irritability ☐ depression ☐ anxiety ☐ fatigue

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: ____

Note _____

Date ____/____/____ Log # _____ Encounter # _____

NAUSEA: Date began: ____ #Emesis/Day ____ Can't retain (check one) Liquids ____ Solids ____

Intensity (1-10 scale): ____ Max in last 7 days: ____ Tolerable level: ____

Extent symptom interferes with (1-10 scale): sleep ____ appetite ____ mobility ____
emotions ____ relationships ____ usual daily activity ____ ability to concentrate ____ QOL ____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ activity ☐ disease process ☐ eating ☐ odor ☐ pain
☐ emotions ☐ surgery ☐ treatment/meds ☐ unknown

Associated Symptoms: ☐ sweating ☐ palpitation ☐ dyspnea ☐ pain ☐ vomiting
☐ dizziness ☐ irritability ☐ depression ☐ anxiety ☐ fatigue

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: ____

Note _____

Date ____/____/____ Log # _____ Encounter # _____

NAUSEA: Date began: ____ #Emesis/Day ____ Can't retain (check one) Liquids ____ Solids ____

Intensity (1-10 scale): ____ Max in last 7 days: ____ Tolerable level: ____

Extent symptom interferes with (1-10 scale): sleep ____ appetite ____ mobility ____
emotions ____ relationships ____ usual daily activity ____ ability to concentrate ____ QOL ____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ activity ☐ disease process ☐ eating ☐ odor ☐ pain
☐ emotions ☐ surgery ☐ treatment/meds ☐ unknown

Associated Symptoms: ☐ sweating ☐ palpitation ☐ dyspnea ☐ pain ☐ vomiting
☐ dizziness ☐ irritability ☐ depression ☐ anxiety ☐ fatigue

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: ____ Note _____

SYMPTOMS

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

FATIGUE: Date Began: ____/____/____

Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____
emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ activity ☐ anemia ☐ anxiety ☐ depression ☐ diarrhea ☐ disease process

☐ infection ☐ insomnia ☐ meds ☐ nausea ☐ nutrition deficiency

☐ pain ☐ emotions ☐ stress ☐ surgery ☐ treatment ☐ unknown

Associated Symptoms: ☐ activity intolerance ☐ anemia ☐ anorexia ☐ anxiety ☐ depression

☐ diarrhea ☐ dizziness ☐ dyspnea ☐ irritability ☐ loss of concentration

☐ nausea/vomiting ☐ pain ☐ palpitation ☐ sweating ☐ unknown ☐ weight change

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note: _____

Date ____/____/____ Log # _____ Encounter # _____

FATIGUE: Date Began: ____/____/____

Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____
emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ activity ☐ anemia ☐ anxiety ☐ depression ☐ diarrhea ☐ disease process

☐ infection ☐ insomnia ☐ meds ☐ nausea ☐ nutrition deficiency

☐ pain ☐ emotions ☐ stress ☐ surgery ☐ treatment ☐ unknown

Associated Symptoms: ☐ activity intolerance ☐ anemia ☐ anorexia ☐ anxiety ☐ depression

☐ diarrhea ☐ dizziness ☐ dyspnea ☐ irritability ☐ loss of concentration

☐ nausea/vomiting ☐ pain ☐ palpitation ☐ sweating ☐ unknown ☐ weight change

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note: _____

Date ____/____/____ Log # _____ Encounter # _____

FATIGUE: Date Began: ____/____/____

Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____
emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ activity ☐ anemia ☐ anxiety ☐ depression ☐ diarrhea ☐ disease process

☐ infection ☐ insomnia ☐ meds ☐ nausea ☐ nutrition deficiency

☐ pain ☐ emotions ☐ stress ☐ surgery ☐ treatment ☐ unknown

Associated Symptoms: ☐ activity intolerance ☐ anemia ☐ anorexia ☐ anxiety ☐ depression

☐ diarrhea ☐ dizziness ☐ dyspnea ☐ irritability ☐ loss of concentration

☐ nausea/vomiting ☐ pain ☐ palpitation ☐ sweating ☐ unknown ☐ weight change

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note: _____

SYMPTOMS

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

FATIGUE: Date Began: ____/____/____

Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____
emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ activity ☐ anemia ☐ anxiety ☐ depression ☐ diarrhea ☐ disease process
☐ infection ☐ insomnia ☐ meds ☐ nausea ☐ nutrition deficiency
☐ pain ☐ emotions ☐ stress ☐ surgery ☐ treatment ☐ unknown

Associated Symptoms: ☐ activity intolerance ☐ anemia ☐ anorexia ☐ anxiety ☐ depression
☐ diarrhea ☐ dizziness ☐ dyspnea ☐ irritability ☐ loss of concentration
☐ nausea/vomiting ☐ pain ☐ palpitation ☐ sweating ☐ unknown ☐ weight change

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note: _____

Date ____/____/____ Log # _____ Encounter # _____

FATIGUE: Date Began: ____/____/____

Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____
emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ activity ☐ anemia ☐ anxiety ☐ depression ☐ diarrhea ☐ disease process
☐ infection ☐ insomnia ☐ meds ☐ nausea ☐ nutrition deficiency
☐ pain ☐ emotions ☐ stress ☐ surgery ☐ treatment ☐ unknown

Associated Symptoms: ☐ activity intolerance ☐ anemia ☐ anorexia ☐ anxiety ☐ depression
☐ diarrhea ☐ dizziness ☐ dyspnea ☐ irritability ☐ loss of concentration
☐ nausea/vomiting ☐ pain ☐ palpitation ☐ sweating ☐ unknown ☐ weight change

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note: _____

Date ____/____/____ Log # _____ Encounter # _____

FATIGUE: Date Began: ____/____/____

Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____
emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ activity ☐ anemia ☐ anxiety ☐ depression ☐ diarrhea ☐ disease process
☐ infection ☐ insomnia ☐ meds ☐ nausea ☐ nutrition deficiency
☐ pain ☐ emotions ☐ stress ☐ surgery ☐ treatment ☐ unknown

Associated Symptoms: ☐ activity intolerance ☐ anemia ☐ anorexia ☐ anxiety ☐ depression
☐ diarrhea ☐ dizziness ☐ dyspnea ☐ irritability ☐ loss of concentration
☐ nausea/vomiting ☐ pain ☐ palpitation ☐ sweating ☐ unknown ☐ weight change

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note: _____

SYMPTOMS

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

FEVER Date Began ____/____/____

Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____

emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ allergies ☐ antibiotic ☐ disease process ☐ infection
☐ meds ☐ surgery ☐ unknown

Associated Symptoms: ☐ aches ☐ anorexia ☐ arthralgia ☐ chills ☐ confusion ☐ cough
☐ diaphoresis ☐ diarrhea ☐ dizziness ☐ dyspnea ☐ fatigue
☐ headache ☐ nasal congestion ☐ nausea ☐ rash ☐ unknown

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note: _____

Date ____/____/____ Log # _____ Encounter # _____

FEVER Date Began: _____

Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____

emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ allergies ☐ antibiotic ☐ disease process ☐ infection
☐ meds ☐ surgery ☐ unknown

Associated Symptoms: ☐ aches ☐ anorexia ☐ arthralgia ☐ chills ☐ confusion ☐ cough
☐ diaphoresis ☐ diarrhea ☐ dizziness ☐ dyspnea ☐ fatigue
☐ headache ☐ nasal congestion ☐ nausea ☐ rash ☐ unknown

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note: _____

Date ____/____/____ Log # _____ Encounter # _____

FEVER Date Began: _____

Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____

emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ allergies ☐ antibiotic ☐ disease process ☐ infection
☐ meds ☐ surgery ☐ unknown

Associated Symptoms: ☐ aches ☐ anorexia ☐ arthralgia ☐ chills ☐ confusion ☐ cough
☐ diaphoresis ☐ diarrhea ☐ dizziness ☐ dyspnea ☐ fatigue
☐ headache ☐ nasal congestion ☐ nausea ☐ rash ☐ unknown

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note: _____

SYMPTOMS

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

FEVER Date Began ____/____/____

Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____
emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ allergies ☐ antibiotic ☐ disease process ☐ infection
☐ meds ☐ surgery ☐ unknown

Associated Symptoms: ☐ aches ☐ anorexia ☐ arthralgia ☐ chills ☐ confusion ☐ cough
☐ diaphoresis ☐ diarrhea ☐ dizziness ☐ dyspnea ☐ fatigue
☐ headache ☐ nasal congestion ☐ nausea ☐ rash ☐ unknown

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note: _____

Date ____/____/____ Log # _____ Encounter # _____

FEVER Date Began: _____

Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____
emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ allergies ☐ antibiotic ☐ disease process ☐ infection
☐ meds ☐ surgery ☐ unknown

Associated Symptoms: ☐ aches ☐ anorexia ☐ arthralgia ☐ chills ☐ confusion ☐ cough
☐ diaphoresis ☐ diarrhea ☐ dizziness ☐ dyspnea ☐ fatigue
☐ headache ☐ nasal congestion ☐ nausea ☐ rash ☐ unknown

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note: _____

Date ____/____/____ Log # _____ Encounter # _____

FEVER Date Began: _____

Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____
emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ allergies ☐ antibiotic ☐ disease process ☐ infection
☐ meds ☐ surgery ☐ unknown

Associated Symptoms: ☐ aches ☐ anorexia ☐ arthralgia ☐ chills ☐ confusion ☐ cough
☐ diaphoresis ☐ diarrhea ☐ dizziness ☐ dyspnea ☐ fatigue
☐ headache ☐ nasal congestion ☐ nausea ☐ rash ☐ unknown

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note: _____

SYMPTOMS

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

INSOMNIA Date Began: ____/____/____

Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Pattern (check one): ☐ WNL ☐ Night-Waking ☐ Increased ☐ Nightmares ☐ Early Waking
☐ Narcolepsy/sleep disorder ☐ Can't fall asleep ☐ Intermittent insomnia

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____
 emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ anxiety ☐ depression ☐ disease process ☐ environ. factors ☐ GI disturbance
☐ meds ☐ N/V ☐ pain ☐ emotions ☐ stress ☐ surgery
☐ unknown ☐ urinary freq.

Associated Symptoms: ☐ anxiety ☐ depression ☐ dizziness ☐ fatigue ☐ irritability
☐ nausea ☐ pain ☐ palpitation ☐ sweating ☐ unknown ☐ vomiting

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note _____

Date ____/____/____ Log # _____ Encounter # _____

INSOMNIA Date Began: ____/____/____

Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Pattern (check one): ☐ WNL ☐ Night-Waking ☐ Increased ☐ Nightmares ☐ Early Waking
☐ Narcolepsy/sleep disorder ☐ Can't fall asleep ☐ Intermittent insomnia

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____
 emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ anxiety ☐ depression ☐ disease process ☐ environ. factors ☐ GI disturbance
☐ meds ☐ N/V ☐ pain ☐ emotions ☐ stress ☐ surgery
☐ unknown ☐ urinary freq.

Associated Symptoms: ☐ anxiety ☐ depression ☐ dizziness ☐ fatigue ☐ irritability
☐ nausea ☐ pain ☐ palpitation ☐ sweating ☐ unknown ☐ vomiting

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note _____

SYMPTOMS

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

INSOMNIA Date Began: ____/____/____

Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Pattern (check one): ☐ WNL ☐ Night-Waking ☐ Increased ☐ Nightmares ☐ Early Waking
☐ Narcolepsy/sleep disorder ☐ Can't fall asleep ☐ Intermittent insomnia

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____
 emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ anxiety ☐ depression ☐ disease process ☐ environ. factors ☐ GI disturbance
☐ meds ☐ N/V ☐ pain ☐ emotions ☐ stress ☐ surgery
☐ unknown ☐ urinary freq.

Associated Symptoms: ☐ anxiety ☐ depression ☐ dizziness ☐ fatigue ☐ irritability
☐ nausea ☐ pain ☐ palpitation ☐ sweating ☐ unknown ☐ vomiting

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note _____

Date ____/____/____ Log # _____ Encounter # _____

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Frequency (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Pattern (check one): ☐ WNL ☐ Night-Waking ☐ Increased ☐ Nightmares ☐ Early Waking
☐ Narcolepsy/sleep disorder ☐ Can't fall asleep ☐ Intermittent insomnia

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____
 emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ anxiety ☐ depression ☐ disease process ☐ environ. factors ☐ GI disturbance
☐ meds ☐ N/V ☐ pain ☐ emotions ☐ stress ☐ surgery
☐ unknown ☐ urinary freq.

Associated Symptoms: ☐ anxiety ☐ depression ☐ dizziness ☐ fatigue ☐ irritability
☐ nausea ☐ pain ☐ palpitation ☐ sweating ☐ unknown ☐ vomiting

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note _____

SYMPTOMS

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

DIARRHEA: Date Began: ____/____/____

Frequency (check one): ☐ 2-3 stools/day ☐ 4-6 stools/day ☐ 7-10 stools/day

Pattern (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Character (check one): ☐ loose ☐ soft ☐ liquid ☐ diarrhea/constipation

Color (check one): ☐ WNL ☐ tarry ☐ pale ☐ yellow ☐ green ☐ black ☐ frank blood

Intensity (1-10 scale): _____ **Max in last 7 days:** _____ **Tolerable level:** _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____

emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Cause: ☐ altered nutrition

☐ disease process

☐ impaction ☐ infection

☐ meds

☐ stress/anxiety

☐ surgery

☐ unknown ☐ virus

Associated Symptoms: ☐ activity intolerance ☐ anorexia ☐ anxiety ☐ bleeding ☐ cramping

☐ depression ☐ distended abd. ☐ dizzy/weak ☐ fatigue ☐ nausea ☐ pain ☐ unknown

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ **Note** _____

Date ____/____/____ Log # _____ Encounter # _____

DIARRHEA: Date Began: ____/____/____

Frequency (check one): ☐ 2-3 stools/day ☐ 4-6 stools/day ☐ 7-10 stools/day

Pattern (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Character (check one): ☐ loose ☐ soft ☐ liquid ☐ diarrhea/constipation

Color (check one): ☐ WNL ☐ tarry ☐ pale ☐ yellow ☐ green ☐ black ☐ frank blood

Intensity (1-10 scale): _____ **Max in last 7 days:** _____ **Tolerable level:** _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____

emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Cause: ☐ altered nutrition

☐ disease process

☐ impaction ☐ infection

☐ meds

☐ stress/anxiety

☐ surgery

☐ unknown ☐ virus

Associated Symptoms: ☐ activity intolerance ☐ anorexia ☐ anxiety ☐ bleeding ☐ cramping

☐ depression ☐ distended abd. ☐ dizzy/weak ☐ fatigue ☐ nausea ☐ pain ☐ unknown

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ **Note** _____

Date ____/____/____ Log # _____ Encounter # _____

DIARRHEA: Date Began: ____/____/____

Frequency (check one): ☐ 2-3 stools/day ☐ 4-6 stools/day ☐ 7-10 stools/day

Pattern (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Character (check one): ☐ loose ☐ soft ☐ liquid ☐ diarrhea/constipation

Color (check one): ☐ WNL ☐ tarry ☐ pale ☐ yellow ☐ green ☐ black ☐ frank blood

Intensity (1-10 scale): _____ **Max in last 7 days:** _____ **Tolerable level:** _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____

emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Cause: ☐ altered nutrition

☐ disease process

☐ impaction ☐ infection

☐ meds

☐ stress/anxiety

☐ surgery

☐ unknown ☐ virus

Associated Symptoms: ☐ activity intolerance ☐ anorexia ☐ anxiety ☐ bleeding ☐ cramping

☐ depression ☐ distended abd. ☐ dizzy/weak ☐ fatigue ☐ nausea ☐ pain ☐ unknown

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ **Note** _____

SYMPTOMS

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

DIARRHEA: Date Began: ____/____/____

Frequency (check one): ☐ 2-3 stools/day ☐ 4-6 stools/day ☐ 7-10 stools/day

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Character (check one): ☐ loose ☐ soft ☐ liquid ☐ diarrhea/constipation

Color (check one): ☐ WNL ☐ tarry ☐ pale ☐ yellow ☐ green ☐ black ☐ frank blood

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____
emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ altered nutrition ☐ disease process ☐ impaction ☐ infection
☐ meds ☐ stress/anxiety ☐ surgery ☐ unknown ☐ virus

Associated Symptoms: ☐ activity intolerance ☐ anorexia ☐ anxiety ☐ bleeding ☐ cramping
☐ depression ☐ distended abd. ☐ dizzy/weak ☐ fatigue ☐ nausea ☐ pain ☐ unknown

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note _____

Date ____/____/____ Log # _____ Encounter # _____

DIARRHEA: Date Began: ____/____/____

Frequency (check one): ☐ 2-3 stools/day ☐ 4-6 stools/day ☐ 7-10 stools/day

Pattern (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Character (check one): ☐ loose ☐ soft ☐ liquid ☐ diarrhea/constipation

Color (check one): ☐ WNL ☐ tarry ☐ pale ☐ yellow ☐ green ☐ black ☐ frank blood

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____
emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ altered nutrition ☐ disease process ☐ impaction ☐ infection
☐ meds ☐ stress/anxiety ☐ surgery ☐ unknown ☐ virus

Associated Symptoms: ☐ activity intolerance ☐ anorexia ☐ anxiety ☐ bleeding ☐ cramping
☐ depression ☐ distended abd. ☐ dizzy/weak ☐ fatigue ☐ nausea ☐ pain ☐ unknown

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note _____

Date ____/____/____ Log # _____ Encounter # _____

DIARRHEA: Date Began: ____/____/____

Frequency (check one): ☐ 2-3 stools/day ☐ 4-6 stools/day ☐ 7-10 stools/day

Pattern (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Character (check one): ☐ loose ☐ soft ☐ liquid ☐ diarrhea/constipation

Color (check one): ☐ WNL ☐ tarry ☐ pale ☐ yellow ☐ green ☐ black ☐ frank blood

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____
emotions _____ relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ altered nutrition ☐ disease process ☐ impaction ☐ infection
☐ meds ☐ stress/anxiety ☐ surgery ☐ unknown ☐ virus

Associated Symptoms: ☐ activity intolerance ☐ anorexia ☐ anxiety ☐ bleeding ☐ cramping
☐ depression ☐ distended abd. ☐ dizzy/weak ☐ fatigue ☐ nausea ☐ pain ☐ unknown

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note _____

SYMPTOMS

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

CONSTIPATION: Date Began ____/____/____

Frequency (check one): ☐ no change ☐ mild ☐ moderate ☐ severe ☐ Ileus (>96 hours)

Bowel Movements in last week: _____

Pattern (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Character (check one): ☐ Hard-Dry ☐ Loose ☐ Soft ☐ Liquid ☐ Diarrhea/Constip

Color (check one): ☐ WNL ☐ tarry ☐ pale ☐ yellow ☐ green ☐ black ☐ frank blood

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____ emotions _____
relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ change in diet ☐ decreased mobility ☐ dehydration ☐ opiate use ☐ other med ☐ unknown

Associated Symptoms: ☐ abdom. distention ☐ abdom. pain ☐ anorexia ☐ cramping ☐ depression

☐ emesis ☐ nausea ☐ pain ☐ rect. fullness ☐ unknown

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note _____

Date ____/____/____ Log # _____ Encounter # _____

CONSTIPATION: Date Began ____/____/____

Frequency (check one): ☐ no change ☐ mild ☐ moderate ☐ severe ☐ Ileus (>96 hours)

Bowel Movements in last week: _____

Pattern (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Character (check one): ☐ Hard-Dry ☐ Loose ☐ Soft ☐ Liquid ☐ Diarrhea/Constip

Color (check one): ☐ WNL ☐ tarry ☐ pale ☐ yellow ☐ green ☐ black ☐ frank blood

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____ emotions _____
relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ change in diet ☐ decreased mobility ☐ dehydration ☐ opiate use ☐ other med ☐ unknown

Associated Symptoms: ☐ abdom. distention ☐ abdom. pain ☐ anorexia ☐ cramping ☐ depression

☐ emesis ☐ nausea ☐ pain ☐ rect. fullness ☐ unknown

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note _____

Date ____/____/____ Log # _____ Encounter # _____

CONSTIPATION: Date Began ____/____/____

Frequency (check one): ☐ no change ☐ mild ☐ moderate ☐ severe ☐ Ileus (>96 hours)

Bowel Movements in last week: _____

Pattern (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Character (check one): ☐ Hard-Dry ☐ Loose ☐ Soft ☐ Liquid ☐ Diarrhea/Constip

Color (check one): ☐ WNL ☐ tarry ☐ pale ☐ yellow ☐ green ☐ black ☐ frank blood

Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____ emotions _____
relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

Prescriptive relief:

Non-Prescriptive relief:

Cause: ☐ change in diet ☐ decreased mobility ☐ dehydration ☐ opiate use ☐ other med ☐ unknown

Associated Symptoms: ☐ abdom. distention ☐ abdom. pain ☐ anorexia ☐ cramping ☐ depression

☐ emesis ☐ nausea ☐ pain ☐ rect. fullness ☐ unknown

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note _____

SYMPTOMS

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

CONSTIPATION: Date Began ____/____/____

Frequency (check one): ☐ no change ☐ mild ☐ moderate ☐ severe ☐ Ileus (>96 hours)

Bowel Movements in last week: _____

Pattern (check one): ☐ intermittent ☐ continuous ☐ unrelenting ☐ patterned

Character (check one): ☐ Hard-Dry ☐ Loose ☐ Soft ☐ Liquid ☐ Diarrhea/Constip

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Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

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Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____

Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____ emotions _____
relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____

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Non-Prescriptive relief:

Cause: ☐ change in diet ☐ decreased mobility ☐ dehydration ☐ opiate use ☐ other med ☐ unknown

Associated Symptoms: ☐ abdom. distention ☐ abdom. pain ☐ anorexia ☐ cramping ☐ depression

☐ emesis ☐ nausea ☐ pain ☐ rect. fullness ☐ unknown

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Associated Symptoms: ☐ abdom. distention ☐ abdom. pain ☐ anorexia ☐ cramping ☐ depression

☐ emesis ☐ nausea ☐ pain ☐ rect. fullness ☐ unknown

Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened

Date ended: _____ Note _____

SYMPTOMS

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

OTHER Date Began: ____/____/____
Frequency (check one): ☐ Intermittent ☐ continuous ☐ unrelenting ☐ patterned
Intensity (1-10 scale): ____ Max in last 7 days: ____ Tolerable level: ____
Extent symptom interferes with (1-10 scale): sleep ____ appetite ____ mobility ____ emotions ____
 relationships ____ usual daily activity ____ ability to concentrate ____ QOL ____
Prescriptive relief: _____ **Non-Prescriptive relief:** _____
Cause: _____
Associated Symptoms: _____
Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened
Date ended: ____/____/____ **Note:** _____

Date ____/____/____ Log # _____ Encounter # _____

OTHER Date Began: ____/____/____
Frequency (check one): ☐ Intermittent ☐ continuous ☐ unrelenting ☐ patterned
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Extent symptom interferes with (1-10 scale): sleep ____ appetite ____ mobility ____ emotions ____
 relationships ____ usual daily activity ____ ability to concentrate ____ QOL ____
Prescriptive relief: _____ **Non-Prescriptive relief:** _____
Cause: _____
Associated Symptoms: _____
Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened
Date ended: ____/____/____ **Note:** _____

Date ____/____/____ Log # _____ Encounter # _____

OTHER Date Began: ____/____/____
Frequency (check one): ☐ Intermittent ☐ continuous ☐ unrelenting ☐ patterned
Intensity (1-10 scale): ____ Max in last 7 days: ____ Tolerable level: ____
Extent symptom interferes with (1-10 scale): sleep ____ appetite ____ mobility ____ emotions ____
 relationships ____ usual daily activity ____ ability to concentrate ____ QOL ____
Prescriptive relief: _____ **Non-Prescriptive relief:** _____
Cause: _____
Associated Symptoms: _____
Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened
Date ended: ____/____/____ **Note:** _____

Date ____/____/____ Log # _____ Encounter # _____

OTHER Date Began: ____/____/____
Frequency (check one): ☐ Intermittent ☐ continuous ☐ unrelenting ☐ patterned
Intensity (1-10 scale): ____ Max in last 7 days: ____ Tolerable level: ____
Extent symptom interferes with (1-10 scale): sleep ____ appetite ____ mobility ____ emotions ____
 relationships ____ usual daily activity ____ ability to concentrate ____ QOL ____
Prescriptive relief: _____ **Non-Prescriptive relief:** _____
Cause: _____
Associated Symptoms: _____
Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened
Date ended: ____/____/____ **Note:** _____

SYMPTOMS

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

OTHER Date Began: ____/____/____
 Frequency (check one): ☐ Intermittent ☐ continuous ☐ unrelenting ☐ patterned
 Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____
 Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____ emotions _____
 relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____
 Prescriptive relief: _____ Non-Prescriptive relief: _____
 Cause: _____
 Associated Symptoms: _____
 Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened
 Date ended: ____/____/____ Note: _____

Date ____/____/____ Log # _____ Encounter # _____

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Date ____/____/____ Log # _____ Encounter # _____

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 Frequency (check one): ☐ Intermittent ☐ continuous ☐ unrelenting ☐ patterned
 Intensity (1-10 scale): _____ Max in last 7 days: _____ Tolerable level: _____
 Extent symptom interferes with (1-10 scale): sleep _____ appetite _____ mobility _____ emotions _____
 relationships _____ usual daily activity _____ ability to concentrate _____ QOL _____
 Prescriptive relief: _____ Non-Prescriptive relief: _____
 Cause: _____
 Associated Symptoms: _____
 Response (check one): ☐ resolved ☐ improved ☐ acceptable ☐ unacceptable ☐ worsened
 Date ended: ____/____/____ Note: _____



ASSESSMENT

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

GENERAL STATUS (PHYSICAL)

Weight: _____ Usual Weight: _____ Height: _____

Systolic: _____ Diastolic: _____ Temp: _____ Respiration: _____ Pulse: _____

Orthostasis ☐ Yes ☐ No

Hearing (check one):

☐ WNL ☐ HOH ☐ Aid ☐ Deaf ☐ Recent Change

Vision (check one):

☐ WNL ☐ No Recent Change ☐ Glasses
☐ Blind Rt ☐ Blind Lt ☐ Blind both

Intake (check one):

☐ WNL ☐ Caloric Deficient ☐ Fluid Deficient

Skin (check one):

☐ WNL ☐ Pale ☐ White ☐ Brown
☐ Reddened ☐ Cyanotic ☐ Jaundiced

Date ____/____/____ Log # _____ Encounter # _____

Systolic: _____ Diastolic: _____ Temp: _____ Respiration: _____ Pulse: _____

Date ____/____/____ Log # _____ Encounter # _____

Systolic: _____ Diastolic: _____ Temp: _____ Respiration: _____ Pulse: _____

Date ____/____/____ Log # _____ Encounter # _____

Systolic: _____ Diastolic: _____ Temp: _____ Respiration: _____ Pulse: _____

Date ____/____/____ Log # ____ Encounter # ____

Systolic: ____ Diastolic: ____ Temp: ____ Respiration: ____ Pulse: ____

Date ____/____/____ Log # ____ Encounter # ____

Systolic: ____ Diastolic: ____ Temp: ____ Respiration: ____ Pulse: ____

Date ____/____/____ Log # ____ Encounter # ____

Systolic: ____ Diastolic: ____ Temp: ____ Respiration: ____ Pulse: ____

Date ____/____/____ Log # ____ Encounter # ____

Systolic: ____ Diastolic: ____ Temp: ____ Respiration: ____ Pulse: ____

Date ____/____/____ Log # ____ Encounter # ____

Systolic: ____ Diastolic: ____ Temp: ____ Respiration: ____ Pulse: ____

Date ____/____/____ Log # ____ Encounter # ____

Systolic: ____ Diastolic: ____ Temp: ____ Respiration: ____ Pulse: ____

Date ____/____/____ Log # ____ Encounter # ____

Systolic: ____ Diastolic: ____ Temp: ____ Respiration: ____ Pulse: ____

Date ____/____/____ Log # ____ Encounter # ____

Systolic: ____ Diastolic: ____ Temp: ____ Respiration: ____ Pulse: ____

DRESSING AND WOUND EXAM

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

DRESSING & WOUND EXAM

Are supplies available? ☐ Yes ☐ No

Can pt change dressing (check one): ☐ Y ☐ N ☐ Needs help

Can pt drain tubes (check one): ☐ Y ☐ N ☐ Needs help

Can pt strip tubing (check one): ☐ Y ☐ N ☐ Needs help

Incision area (draw incision on paper form)

Side: ☐ Left ☐ Right ☐ Both _____

Edges (check one): Well approx. _____ Gaping _____ Dehiscence _____ Size _____ cm

Dressing changed within ☐ last hour ☐ last 3 hrs ☐ last 6 hrs ☐ last 12 hrs ☐ last 24 hrs

Drainage appearance: ☐ Serous ☐ Sero-Sang ☐ Sanguineous ☐ Purulent ☐ Clear ☐ None

Secretion consistency: ☐ thin & flowing ☐ thin with tissue/coag ☐ thick & pasty ☐ none

Stain size _____ cm

Is the incision area extremely : ☐ warm ☐ red ☐ swollen ☐ tender

Hematoma: ☐ None ☐ less than 1 cm ☐ less than 2 cm ☐ less than 4 cm ☐ over 4cm _____

Seroma (elevation): ☐ None ☐ minimal ($\geq .05$ cm) ☐ mild (≥ 1 cm) ☐ moderate (≥ 1.5 cm)

☐ marked (>1.5 cm) ☐ Diameter in cm _____

Closed Drainage

Amount: ☐ unknown ☐ none ☐ less than 30cc ☐ more than 30cc ☐ more than 100cc

Appearance: ☐ Serous ☐ Sero-Sang ☐ Sanguineous ☐ Purulent ☐ Clear ☐ None

Consistency: ☐ thin & flowing ☐ thin with tissue/coag ☐ thick & pasty ☐ none

Tube clog? ☐ Yes ☐ No

HANDOUTS FIRST VISIT: Drainage Chart, Resource List, ROM booklet

Date ____/____/____ Log # _____ Encounter # _____

DRESSING & WOUND EXAM

Are supplies available? ☐ Yes ☐ No

Can pt change dressing (check one): ☐ Y ☐ N ☐ Needs help

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Can pt strip tubing (check one): ☐ Y ☐ N ☐ Needs help

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Consistency: ☐ thin & flowing ☐ thin with tissue/coag ☐ thick & pasty ☐ none

Tube clog? ☐ Yes ☐ No

HANDOUTS FIRST VISIT: Drainage Chart, Resource List, ROM booklet

DRESSING AND WOUND EXAM

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

DRESSING & WOUND EXAM

Are supplies available? ☐ Yes ☐ No

Can pt change dressing (check one): ☐ Y ☐ N ☐ Needs help

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Tube clog? ☐ Yes ☐ No

HANDOUTS FIRST VISIT: Drainage Chart, Resource List, ROM booklet

Date ____/____/____ Log # _____ Encounter # _____

DRESSING & WOUND EXAM

Are supplies available? ☐ Yes ☐ No

Can pt change dressing (check one): ☐ Y ☐ N ☐ Needs help

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Incision area (draw incision on paper form)

Side: ☐ Left ☐ Right ☐ Both _____

Edges (check one): Well approx. ☐ Gaping ☐ Dehiscence ☐ Size _____ cm

Dressing changed within ☐ last hour ☐ last 3 hrs ☐ last 6 hrs ☐ last 12 hrs ☐ last 24 hrs

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Consistency: ☐ thin & flowing ☐ thin with tissue/coag ☐ thick & pasty ☐ none

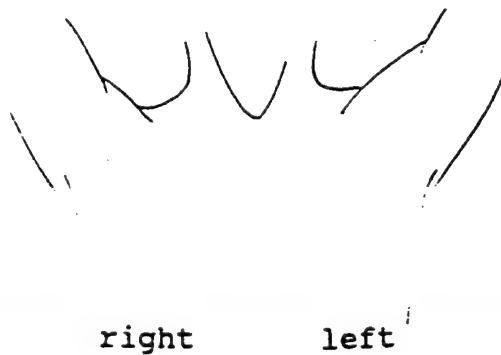
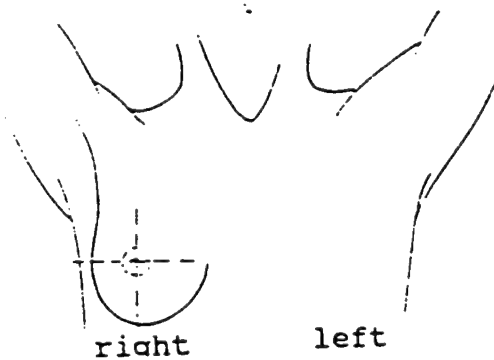
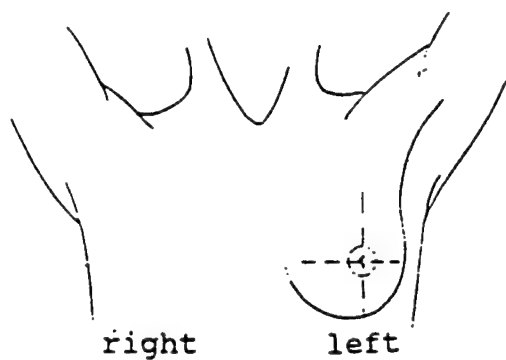
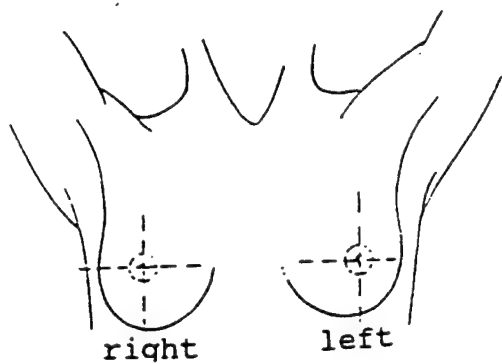
Tube clog? ☐ Yes ☐ No

HANDOUTS FIRST VISIT: Drainage Chart, Resource List, ROM booklet



Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

[illegible]

BSE AND LYMPHEDEMA

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

Breast Self-Exam

Can patient verbalize/demonstrate:

Flat finger technique: ☐ Yes ☐ No ☐ Needs Help

Circle method to cover breast: ☐ Yes ☐ No ☐ Needs Help

Correct hand to use: ☐ Yes ☐ No ☐ Needs Help

Correct time for self-exam: ☐ Yes ☐ No ☐ Needs Help

Need to check for lumps/knots: ☐ Yes ☐ No ☐ Needs Help

Method of expressing fluid: ☐ Yes ☐ No ☐ Needs Help

Lymphedema Prevention

Node removal effects: ☐ Yes ☐ No ☐ Needs Help

Arm elevation/fist squeezing technique: ☐ Yes ☐ No ☐ Needs Help

Strategies to prevent skin breaks: ☐ Yes ☐ No ☐ Needs Help

Ways to avoid squeezing pressure on arm: ☐ Yes ☐ No ☐ Needs Help

Is Phantom Breast sensation present: ☐ Always ☐ Most of the time ☐ Sometimes ☐ Never

HANDOUTS SECOND VISIT: Lymphedema Prevention Sheet, Shower Card

SENSATION, FINE MOTOR and QUALITY OF LIFE

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

RANGE OF MOTION

Surgical Side: ☐ Left ☐ Right ☐ Both

Can patient lift affected arm:

| <i>Extent patient can lift affected arm</i> | Right | Left |
|---|-------|------|
| 1. Not at all | | |
| 2. Very little | | |
| 3. About half | | |
| 4. Near fully | | |
| 5. Fully | | |

Pins and needles sensation in arm: ☐ always ☐ most of the time ☐ some time ☐ never

Return of Pre-surgery sensation in arm: ☐ completely ☐ mostly ☐ partially ☐ not at all

Tightness of chest wall: ☐ always ☐ most of the time ☐ sometime ☐ never

Using the hand on the surgical side, is patient now able to:

Pick up a nickel? ☐ always able ☐ usually ☐ sometimes ☐ rarely ☐ unable

Touch thumb to each finger? ☐ always able ☐ usually ☐ sometimes ☐ rarely ☐ unable

Pre-surgery, with the hand on the surgical side, was patient able to:

Pick up a nickel? ☐ always able ☐ usually ☐ sometimes ☐ rarely ☐ unable

Touch thumb to each finger? ☐ always able ☐ usually ☐ sometimes ☐ rarely ☐ unable

Date ____/____/____ Log # _____ Encounter # _____

QUALITY OF LIFE (first visit - below is nurse check-list)

Was patient's overall physical well-being reviewed? ☐ Yes ☐ No

Did you review patient's social/family well-being, e.g.
communication with partner, family adjustments? ☐ Yes ☐ No

Reviewed relationships and access to Mds/Health professionals? ☐ Yes ☐ No

Reviewed functional status - work, life enjoyment? ☐ Yes ☐ No

Reviewed self-perception, body image, coping with stressors? ☐ Yes ☐ No

Note: (problems, interventions)

SENSATION, FINE MOTOR and QUALITY OF LIFE

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

RANGE OF MOTIONSurgical Side: ☐ Left ☐ Right ☐ Both

Can patient lift affected arm:

| <i>Extent patient can lift affected arm</i> | Right | Left |
|---|-------|------|
| 1. Not at all | | |
| 2. Very little | | |
| 3. About half | | |
| 4. Near fully | | |
| 5. Fully | | |

Pins and needles sensation in arm: ☐ always ☐ most of the time ☐ some time ☐ neverReturn of Pre-surgery sensation in arm: ☐ completely ☐ mostly ☐ partially ☐ not at allTightness of chest wall: ☐ always ☐ most of the time ☐ sometime ☐ neverUsing the hand on the surgical side, is patient now able to:Pick up a nickel? ☐ always able ☐ usually ☐ sometimes ☐ rarely ☐ unableTouch thumb to each finger? ☐ always able ☐ usually ☐ sometimes ☐ rarely ☐ unable

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Date ____/____/____ Log # _____ Encounter # _____

QUALITY OF LIFE (first visit - below is nurse check-list)Was patient's overall physical well-being reviewed? ☐ Yes ☐ NoDid you review patient's social/family well-being, e.g.
communication with partner, family adjustments? ☐ Yes ☐ NoReviewed relationships and access to Mds/Health professionals? ☐ Yes ☐ NoReviewed functional status - work, life enjoyment? ☐ Yes ☐ NoReviewed self-perception, body image, coping with stressors? ☐ Yes ☐ No

Note: (problems, interventions)

NURSING ASSESSMENT

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

ANXIETY Date Began: ____/____/____ **On anti-anxiety medication now:** ☐ Yes ☐ No
Frequency (check one): ☐ Intermittent ☐ continuous ☐ unrelenting ☐ patterned
Intensity (1-10 scale): ____ Max in last 7 days: ____
Extent symptom interferes with (1-10 scale): sleep ____ appetite ____ mobility ____
 emotions ____ relationships ____ usual daily activity ____ ability to concentrate ____ QOL ____
Prescriptive relief: **Non-prescriptive relief:**
Cause: (choose only 1) ☐ cancer diagnosis ☐ anticipation of future cancer tx (surgery, RT, chemo)
☐ disease process ☐ node status ☐ fear ☐ hyperthyroid ☐ lifestyle ☐ impact on self/family
☐ changing relationship ☐ ineffective coping ☐ rolechanges
Clinical markers: Motor: ☐ tension ☐ trembling ☐ shakiness ☐ restlessness
☐ sighing ☐ respiration ☐ unable to relax ☐ pressured speech
Autonomic: (choose only 1) ☐ sweating ☐ tachycardia ☐ tachypnea ☐ cold clammy hand
☐ dry mouth ☐ hot/cold spells ☐ dizziness ☐ parenthesis ☐ GI distress
Mood: ☐ irritable ☐ apprehensive ☐ anticipating doom ☐ general fearfulness
Hyperactivity: ☐ Diff. concentrating ☐ trouble sleeping ☐ interim sleep ☐ unrestful sleep ☐ fatigue on waking
Date ended: ____ **Note** _____

Date ____/____/____ Log # _____ Encounter # _____

ANXIETY Date Began: ____/____/____ **On anti-anxiety medication now:** ☐ Yes ☐ No
Frequency (check one): ☐ Intermittent ☐ continuous ☐ unrelenting ☐ patterned
Intensity (1-10 scale): ____ Max in last 7 days: ____
Extent symptom interferes with (1-10 scale): sleep ____ appetite ____ mobility ____
 emotions ____ relationships ____ usual daily activity ____ ability to concentrate ____ QOL ____
Prescriptive relief: **Non-prescriptive relief:**
Cause: (choose only 1) ☐ cancer diagnosis ☐ anticipation of future cancer tx (surgery, RT, chemo)
☐ disease process ☐ node status ☐ fear ☐ hyperthyroid ☐ lifestyle ☐ impact on self/family
☐ changing relationship ☐ ineffective coping ☐ rolechanges
Clinical markers: Motor: ☐ tension ☐ trembling ☐ shakiness ☐ restlessness
☐ sighing ☐ respiration ☐ unable to relax ☐ pressured speech
Autonomic: (choose only 1) ☐ sweating ☐ tachycardia ☐ tachypnea ☐ cold clammy hand
☐ dry mouth ☐ hot/cold spells ☐ dizziness ☐ parenthesis ☐ GI distress
Mood: ☐ irritable ☐ apprehensive ☐ anticipating doom ☐ general fearfulness
Hyperactivity: ☐ Diff. concentrating ☐ trouble sleeping ☐ interim sleep ☐ unrestful sleep ☐ fatigue on waking
Date ended: ____ **Note** _____

Date ____/____/____ Log # _____ Encounter # _____

ANXIETY Date Began: ____/____/____ **On anti-anxiety medication now:** ☐ Yes ☐ No
Frequency (check one): ☐ Intermittent ☐ continuous ☐ unrelenting ☐ patterned
Intensity (1-10 scale): ____ Max in last 7 days: ____
Extent symptom interferes with (1-10 scale): sleep ____ appetite ____ mobility ____
 emotions ____ relationships ____ usual daily activity ____ ability to concentrate ____ QOL ____
Prescriptive relief: **Non-prescriptive relief:**
Cause: (choose only 1) ☐ cancer diagnosis ☐ anticipation of future cancer tx (surgery, RT, chemo)
☐ disease process ☐ node status ☐ fear ☐ hyperthyroid ☐ lifestyle ☐ impact on self/family
☐ changing relationship ☐ ineffective coping ☐ rolechanges
Clinical markers: Motor: ☐ tension ☐ trembling ☐ shakiness ☐ restlessness
☐ sighing ☐ respiration ☐ unable to relax ☐ pressured speech
Autonomic: (choose only 1) ☐ sweating ☐ tachycardia ☐ tachypnea ☐ cold clammy hand
☐ dry mouth ☐ hot/cold spells ☐ dizziness ☐ parenthesis ☐ GI distress
Mood: ☐ irritable ☐ apprehensive ☐ anticipating doom ☐ general fearfulness
Hyperactivity: ☐ Diff. concentrating ☐ trouble sleeping ☐ interim sleep ☐ unrestful sleep ☐ fatigue on waking
Date ended: ____ **Note** _____

NURSING ASSESSMENT

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

ANXIETY Date Began: ____/____/____ **On anti-anxiety medication now:** ☐ Yes ☐ No
Frequency (check one): ☐ Intermittent ☐ continuous ☐ unrelenting ☐ patterned
Intensity (1-10 scale): ____ Max in last 7 days: ____
Extent symptom interferes with (1-10 scale): sleep ____ appetite ____ mobility ____
 emotions ____ relationships ____ usual daily activity ____ ability to concentrate ____ QOL ____
Prescriptive relief: **Non-prescriptive relief:**
Cause: (choose only 1) ☐ cancer diagnosis ☐ anticipation of future cancer tx (surgery, RT, chemo)
☐ disease process ☐ node status ☐ fear ☐ hyperthyroid ☐ lifestyle ☐ impact on self/family
☐ changing relationship ☐ ineffective coping ☐ rolechanges
Clinical markers: Motor: ☐ tension ☐ trembling ☐ shakiness ☐ restlessness
☐ sighing ☐ respiration ☐ unable to relax ☐ pressured speech
Autonomic: (choose only 1) ☐ sweating ☐ tachycardia ☐ tachypnea ☐ cold clammy hand
☐ dry mouth ☐ hot/cold spells ☐ dizziness ☐ parenthesis ☐ GI distress
Mood: ☐ irritable ☐ apprehensive ☐ anticipating doom ☐ general fearfulness
Hyperactivity: ☐ Diff. concentrating ☐ trouble sleeping ☐ interim sleep ☐ unrestful sleep ☐ fatigue on waking
Date ended: ____ **Note** _____

Date ____/____/____ Log # _____ Encounter # _____

ANXIETY Date Began: ____/____/____ **On anti-anxiety medication now:** ☐ Yes ☐ No
Frequency (check one): ☐ Intermittent ☐ continuous ☐ unrelenting ☐ patterned
Intensity (1-10 scale): ____ Max in last 7 days: ____
Extent symptom interferes with (1-10 scale): sleep ____ appetite ____ mobility ____
 emotions ____ relationships ____ usual daily activity ____ ability to concentrate ____ QOL ____
Prescriptive relief: **Non-prescriptive relief:**
Cause: (choose only 1) ☐ cancer diagnosis ☐ anticipation of future cancer tx (surgery, RT, chemo)
☐ disease process ☐ node status ☐ fear ☐ hyperthyroid ☐ lifestyle ☐ impact on self/family
☐ changing relationship ☐ ineffective coping ☐ rolechanges
Clinical markers: Motor: ☐ tension ☐ trembling ☐ shakiness ☐ restlessness
☐ sighing ☐ respiration ☐ unable to relax ☐ pressured speech
Autonomic: (choose only 1) ☐ sweating ☐ tachycardia ☐ tachypnea ☐ cold clammy hand
☐ dry mouth ☐ hot/cold spells ☐ dizziness ☐ parenthesis ☐ GI distress
Mood: ☐ irritable ☐ apprehensive ☐ anticipating doom ☐ general fearfulness
Hyperactivity: ☐ Diff. concentrating ☐ trouble sleeping ☐ interim sleep ☐ unrestful sleep ☐ fatigue on waking
Date ended: ____ **Note** _____

Date ____/____/____ Log # _____ Encounter # _____

ANXIETY Date Began: ____/____/____ **On anti-anxiety medication now:** ☐ Yes ☐ No
Frequency (check one): ☐ Intermittent ☐ continuous ☐ unrelenting ☐ patterned
Intensity (1-10 scale): ____ Max in last 7 days: ____
Extent symptom interferes with (1-10 scale): sleep ____ appetite ____ mobility ____
 emotions ____ relationships ____ usual daily activity ____ ability to concentrate ____ QOL ____
Prescriptive relief: **Non-prescriptive relief:**
Cause: (choose only 1) ☐ cancer diagnosis ☐ anticipation of future cancer tx (surgery, RT, chemo)
☐ disease process ☐ node status ☐ fear ☐ hyperthyroid ☐ lifestyle ☐ impact on self/family
☐ changing relationship ☐ ineffective coping ☐ rolechanges
Clinical markers: Motor: ☐ tension ☐ trembling ☐ shakiness ☐ restlessness
☐ sighing ☐ respiration ☐ unable to relax ☐ pressured speech
Autonomic: (choose only 1) ☐ sweating ☐ tachycardia ☐ tachypnea ☐ cold clammy hand
☐ dry mouth ☐ hot/cold spells ☐ dizziness ☐ parenthesis ☐ GI distress
Mood: ☐ irritable ☐ apprehensive ☐ anticipating doom ☐ general fearfulness
Hyperactivity: ☐ Diff. concentrating ☐ trouble sleeping ☐ interim sleep ☐ unrestful sleep ☐ fatigue on waking
Date ended: ____ **Note** _____

NURSING ASSESSMENT

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

DEPRESSION **Date Began:** ____/____/____ **On anti-depressant now:** ☐ Yes ☐ No
Frequency (check one): ☐ Intermittent ☐ continuous ☐ unrelenting ☐ patterned
Intensity (1-10 scale):____ **Max in last 7 days:**____
Extent symptom interferes with (1-10 scale): sleep____ appetite____ mobility____ emotions____
 relationships____ usual daily activity____ ability to concentrate____ QOL____
Cause: (choose not more than 2) ☐ cancer dx ☐ disease process ☐ surgery ☐ chronic illness
 ☐ lifestyle (EOTH?) ☐ meds ☐ family problems
Previous dx of depression? ☐ yes ☐ no
Risk 1: (choose only 1) ☐ pain ☐ low energy ☐ reduced pleasure ☐ Hx of depression
 ☐ Hx suicide ☐ apathy ☐ irritability ☐ overt sadness ☐ sex complaints
 ☐ substance abuse ☐ comorbid ☐ cancer event ☐ non-ca event
Risk 2: (choose only 1) ☐ pain ☐ low energy ☐ reduced pleasure ☐ Hx of depression
 ☐ Hx suicide ☐ apathy ☐ irritability ☐ overt sadness ☐ sex complaints
 ☐ substance abuse ☐ comorbid ☐ cancer event ☐ non-ca event
Criterion Set A: ☐ depressed mood daily ☐ apathy daily ☐ both depression and apathy daily ☐ neither
Criterion Set B: (choose up to 4) ☐ weight loss/gain ☐ insomnia/hypersomnia ☐ psychomotor(agitation/retardation)
 ☐ fatigue ☐ low self esteem ☐ impaired concentration ☐ suicidal ideation
Date ended: **Note** _____

Date / / Log # Encounter #

DEPRESSION **Date Began:** ____/____/____ **On anti-depressant now:** ☐ Yes ☐ No

Frequency (check one): ☐ Intermittent ☐ continuous ☐ unrelenting ☐ patterned

Intensity (1-10 scale): ____ **Max in last 7 days:** ____

Extent symptom interferes with (1-10 scale): sleep ____ appetite ____ mobility ____ emotions ____
relationships ____ usual daily activity ____ ability to concentrate ____ QOL ____

Cause: (choose not more than 2) ☐ cancer dx ☐ disease process ☐ surgery ☐ chronic illness
☐ lifestyle (EOTH?) ☐ meds ☐ family problems

Previous dx of depression? ☐ yes ☐ no

Risk 1: (choose only 1) ☐ pain ☐ low energy ☐ reduced pleasure ☐ Hx of depression
☐ Hx suicide ☐ apathy ☐ irritability ☐ overt sadness ☐ sex complaints
☐ substance abuse ☐ comorbid ☐ cancer event ☐ non-ca event

Risk 2: (choose only 1) ☐ pain ☐ low energy ☐ reduced pleasure ☐ Hx of depression
☐ Hx suicide ☐ apathy ☐ irritability ☐ overt sadness ☐ sex complaints
☐ substance abuse ☐ comorbid ☐ cancer event ☐ non-ca event

Criterion Set A: ☐ depressed mood daily ☐ apathy daily ☐ both depression and apathy daily ☐ neither

Criterion Set B: (choose up to 4) ☐ weight loss/gain ☐ insomnia/hypersomnia ☐ psychomotor (agitation/retardation)
☐ fatigue ☐ low self esteem ☐ impaired concentration ☐ suicidal ideation

Date ended: _____ **Note** _____

NURSING ASSESSMENT

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

DEPRESSION **Date Began:** ____/____/____ **On anti-depressant now:** ☐ Yes ☐ No
Frequency (check one): ☐ Intermittent ☐ continuous ☐ unrelenting ☐ patterned
Intensity (1-10 scale):_____ Max in last 7 days: _____
Extent symptom interferes with (1-10 scale): sleep____ appetite____ mobility____ emotions____
 relationships____ usual daily activity____ ability to concentrate____ QOL____
Cause: (choose not more than 2) ☐ cancer dx ☐ disease process ☐ surgery ☐ chronic illness
 ☐ lifestyle (EOTH?) ☐ meds ☐ family problems
Previous dx of depression? ☐ yes ☐ no
Risk 1: (choose only 1) ☐ pain ☐ low energy ☐ reduced pleasure ☐ Hx of depression
 ☐ Hx suicide ☐ apathy ☐ irritability ☐ overt sadness ☐ sex complaints
 ☐ substance abuse ☐ comorbid ☐ cancer event ☐ non-ca event
Risk 2: (choose only 1) ☐ pain ☐ low energy ☐ reduced pleasure ☐ Hx of depression
 ☐ Hx suicide ☐ apathy ☐ irritability ☐ overt sadness ☐ sex complaints
 ☐ substance abuse ☐ comorbid ☐ cancer event ☐ non-ca event
Criterion Set A: ☐ depressed mood daily ☐ apathy daily ☐ both depression and apathy daily ☐ neither
Criterion Set B: (choose up to 4) ☐ weight loss/gain ☐ insomnia/hypersomnia ☐ psychomotor(agitation/retardation)
 ☐ fatigue ☐ low self esteem ☐ impaired concentration ☐ suicidal ideation
Date ended: **Note** _____

Date / / Log # Encounter #

DEPRESSION

Date Begun: ____/____/____

On anti-depressant now: ☐ Yes ☐ No

Frequency (check one): ☐ Intermittent ☐ continuous ☐ unrelenting ☐ patterned

Intensity (1-10 scale): ____ **Max in last 7 days:** ____

Extent symptom interferes with (1-10 scale): sleep ____ appetite ____ mobility ____ emotions ____
relationships ____ usual daily activity ____ ability to concentrate ____ QOL ____

Cause: (choose not more than 2) ☐ cancer dx ☐ disease process ☐ surgery ☐ chronic illness
☐ lifestyle (EOTH?) ☐ meds ☐ family problems

Previous dx of depression? ☐ yes ☐ no

Risk 1: (choose only 1) ☐ pain ☐ low energy ☐ reduced pleasure ☐ Hx of depression
☐ Hx suicide ☐ apathy ☐ irritability ☐ overt sadness ☐ sex complaints
☐ substance abuse ☐ comorbid ☐ cancer event ☐ non-ca event

Risk 2: (choose only 1) ☐ pain ☐ low energy ☐ reduced pleasure ☐ Hx of depression
☐ Hx suicide ☐ apathy ☐ irritability ☐ overt sadness ☐ sex complaints
☐ substance abuse ☐ comorbid ☐ cancer event ☐ non-ca event

Criterion Set A: ☐ depressed mood daily ☐ apathy daily ☐ both depression and apathy daily ☐ neither

Criterion Set B: (choose up to 4) ☐ weight loss/gain ☐ insomnia/hypersomnia ☐ psychomotor(agitation/retardation)
☐ fatigue ☐ low self esteem ☐ impaired concentration ☐ suicidal ideation

Date ended: _____ **Note** _____

NEW/ONGOING PATIENT PROBLEMS

Name _____ ID# _____ Date ____/____/____ Log # _____ **Encounter # 1**

S: (SUBJECTIVE/PT COMMENTS - See general assessment and symptom section)

O: (OBJECTIVE/NURSE OBSERVATIONS - See general assessment and symptom section)

A: (ASSESSMENT/OVERALL PT STATUS - See problem list)

P: (PLAN/GENERAL OVERALL PLAN FOR PT - See intervention list)

1. _____ Problem Code: _____ ICD Code: _____

2. _____ Problem Code: _____ ICD Code: _____

Date ____/____/____ Log # _____ **Encounter # 2**

S: (SUBJECTIVE/PT COMMENTS - See general assessment and symptom section)

O: (OBJECTIVE/NURSE OBSERVATIONS - See general assessment and symptom section)

A: (ASSESSMENT/OVERALL PT STATUS - See problem list)

P: (PLAN/GENERAL OVERALL PLAN FOR PT - See intervention list)

| | | | |
|-----|------------------------------------|--------------------|------------------|
| 1. | Constipation | Problem Code: 1580 | ICD Code: 564.0 |
| 2. | Pain | Problem Code: 2380 | ICD Code: 611.71 |
| 3. | Activity intolerance | Problem Code: 1020 | ICD Code: 780.7 |
| 4. | Quality of life | Problem Code: 2479 | ICD Code: V62.89 |
| 5. | Knowledge deficit, milking drain | Problem Code: 2144 | ICD Code: V62.3 |
| 6. | Knowledge deficit, empty drain | Problem Code: 2162 | ICD Code: V62.3 |
| 7. | Knowledge deficit, record drainage | Problem Code: 2185 | ICD Code: V62.3 |
| 8. | Consultation - report to doctor | Problem Code: 1585 | ICD Code: V65.8 |
| 9. | | Problem Code: | ICD Code: |
| 10. | | Problem Code: | ICD Code: |
| 11. | | Problem Code: | ICD Code: |
| 12. | | Problem Code: | ICD Code: |
| 13. | | Problem Code: | ICD Code: |
| 14. | | Problem Code: | ICD Code: |
| 15. | | Problem Code: | ICD Code: |
| 16. | | Problem Code: | ICD Code: |

NEW/ONGOING PATIENT PROBLEMS

Name _____ ID# _____ Date ____/____/____ Log # _____ **Encounter # 3**

S: (SUBJECTIVE/PT COMMENTS - See general assessment and symptom section)

O: (OBJECTIVE/NURSE OBSERVATIONS - See general assessment and symptom section)

A: (ASSESSMENT/OVERALL PT STATUS - See problem list)

P: (PLAN/GENERAL OVERALL PLAN FOR PT - See intervention list)

1. _____ Problem Code: _____ ICD Code: _____

2. _____ Problem Code: _____ ICD Code: _____

Date ____/____/____ Log # _____ **Encounter # 4**

S: (SUBJECTIVE/PT COMMENTS - See general assessment and symptom section)

O: (OBJECTIVE/NURSE OBSERVATIONS - See general assessment and symptom section)

A: (ASSESSMENT/OVERALL PT STATUS - See problem list)

P: (PLAN/GENERAL OVERALL PLAN FOR PT - See intervention list)

| | | | |
|-----|------------------------------------|--------------------|------------------|
| 1. | Constipation | Problem Code: 1580 | ICD Code: 564.0 |
| 2. | Pain | Problem Code: 2380 | ICD Code: 611.71 |
| 3. | Activity intolerance | Problem Code: 1020 | ICD Code: 780.7 |
| 4. | Quality of life | Problem Code: 2479 | ICD Code: V62.89 |
| 5. | Skin integrity | Problem Code: 2675 | ICD Code: 879.0 |
| 6. | Knowledge deficit, dressing change | Problem Code: 2164 | ICD Code: V62.3 |
| 7. | Knowledge deficit, milk drain | Problem Code: 2144 | ICD Code: V62.3 |
| 8. | Knowledge deficit, empty drain | Problem Code: 2162 | ICD Code: V62.3 |
| 9. | Knowledge deficit, record drainage | Problem Code: 2185 | ICD Code: V62.3 |
| 10. | Education - lymphedema | Problem Code: 2224 | ICD Code: V62.3 |
| 11. | Education - BSE | Problem Code: 2155 | ICD Code: V62.3 |
| 12. | Education - ROM | Problem Code: 2146 | ICD Code: V62.3 |
| 13. | Consultation - report to doctor | Problem Code: 1585 | ICD Code: V65.8 |
| 14. | | Problem Code: | ICD Code: |
| 15. | | Problem Code: | ICD Code: |
| 16. | | Problem Code: | ICD Code: |
| 17. | | Problem Code: | ICD Code: |
| 18. | | Problem Code: | ICD Code: |

NEW/ONGOING PATIENT PROBLEMS

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

S: (SUBJECTIVE/PT COMMENTS - See general assessment and symptom section)

O: (OBJECTIVE/NURSE OBSERVATIONS - See general assessment and symptom section)

A: (ASSESSMENT/OVERALL PT STATUS - See problem list)

P: (PLAN/GENERAL OVERALL PLAN FOR PT - See intervention list)

All problems listed below must have supporting data listed under either S or O above

- | | | |
|----|---------------------|-----------------|
| 1. | Problem Code: _____ | ICD Code: _____ |
| 2. | Problem Code: _____ | ICD Code: _____ |
| 3. | Problem Code: _____ | ICD Code: _____ |
| 4. | Problem Code: _____ | ICD Code: _____ |
| 5. | Problem Code: _____ | ICD Code: _____ |
| 6. | Problem Code: _____ | ICD Code: _____ |

Date ____/____/____ Log # _____ Encounter # _____

S: (SUBJECTIVE/PT COMMENTS - See general assessment and symptom section)

O: (OBJECTIVE/NURSE OBSERVATIONS - See general assessment and symptom section)

A: (ASSESSMENT/OVERALL PT STATUS - See problem list)

P: (PLAN/GENERAL OVERALL PLAN FOR PT - See intervention list)

All problems listed below must have supporting data listed under either S or O above

- | | | |
|----|---------------------|-----------------|
| 1. | Problem Code: _____ | ICD Code: _____ |
| 2. | Problem Code: _____ | ICD Code: _____ |
| 3. | Problem Code: _____ | ICD Code: _____ |
| 4. | Problem Code: _____ | ICD Code: _____ |
| 5. | Problem Code: _____ | ICD Code: _____ |
| 6. | Problem Code: _____ | ICD Code: _____ |

NEW/ONGOING PATIENT PROBLEMS

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

S: (SUBJECTIVE/PT COMMENTS - See general assessment and symptom section)

O: (OBJECTIVE/NURSE OBSERVATIONS - See general assessment and symptom section)

A: (ASSESSMENT/OVERALL PT STATUS - See problem list)

P: (PLAN/GENERAL OVERALL PLAN FOR PT - See intervention list)

All problems listed below must have supporting data listed under either S or O above

| | | |
|----------|---------------------|-----------------|
| 1. _____ | Problem Code: _____ | ICD Code: _____ |
| 2. _____ | Problem Code: _____ | ICD Code: _____ |
| 3. _____ | Problem Code: _____ | ICD Code: _____ |
| 4. _____ | Problem Code: _____ | ICD Code: _____ |
| 5. _____ | Problem Code: _____ | ICD Code: _____ |
| 6. _____ | Problem Code: _____ | ICD Code: _____ |

Date ____/____/____ Log # _____ Encounter # _____

S: (SUBJECTIVE/PT COMMENTS - See general assessment and symptom section)

O: (OBJECTIVE/NURSE OBSERVATIONS - See general assessment and symptom section)

A: (ASSESSMENT/OVERALL PT STATUS - See problem list)

P: (PLAN/GENERAL OVERALL PLAN FOR PT - See intervention list)

All problems listed below must have supporting data listed under either S or O above

| | | |
|----------|---------------------|-----------------|
| 1. _____ | Problem Code: _____ | ICD Code: _____ |
| 2. _____ | Problem Code: _____ | ICD Code: _____ |
| 3. _____ | Problem Code: _____ | ICD Code: _____ |
| 4. _____ | Problem Code: _____ | ICD Code: _____ |
| 5. _____ | Problem Code: _____ | ICD Code: _____ |
| 6. _____ | Problem Code: _____ | ICD Code: _____ |

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 1

Problem/DX: _____

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 1

Problem/DX: _____

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 2

Problem/DX: **Constipation**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____

days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Constipation** **ASSES_1460** Date entered: _____

Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____

Current visit date

Date eval ended

Intervention: **Medication** **TEACH_2850** Date entered: _____

Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____

Current visit date

Date eval ended

Intervention: **OTC medications** **PRESC_3120** Date entered: _____

Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____

Current visit date

Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____

Current visit date

Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 2

Problem/DX: **Pain**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Pain control** **ASSES_3140**

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: **Medication** **TEACH_2850**

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 2

Problem/DX: **Activity intolerance**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Fatigue**

ASSES_2000

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: **Sleep/rest hygiene**

TEACH_3638

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 2

Problem/DX: **Quality of life**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Quality of life** **ASSES_3381**

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated
Date eval ended

Intervention: **Give educational materials** **TEACH_2220**

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated
Date eval ended

Intervention: **Support re individual** **COUNS_3694**

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated
Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated
Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 2

Problem/DX: **Knowledge deficit - milk drain**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Milk drainage tube - pt** **TEACH_3214** Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 2

Problem/DX: **Knowledge deficit - empty drain**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Empty drain - pt** **TEACH_3213** Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 2

Problem/DX: **Knowledge deficit - record drainage**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Recording drainage - pt** **TEACH_3216** Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 2

Problem/DX: **Consultation - report to doctor**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Week 1 care report to surgeon** **REPORT_8050** Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 3

Problem/DX: _____

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 3

Problem/DX: _____

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 4

Problem/DX: **Constipation**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Constipation** EVAL **1470**

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # **4**

Problem/DX: **Pain**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **OTC medications** **PRESC_3120** Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: **Pain control** **EVAL_3150** Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 4

Problem/DX: **Activity intolerance**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Fatigue**

EVAL_2010

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 4

Problem/DX: **Quality of life**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Quality of life** EVAL_3382

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: **Support group** REFER_5355

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 4

Problem/DX: **Skin integrity**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Skin care - wound** **ASSES_3630** Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____

Current visit date

Date intervention initiated
Date eval ended

Intervention: **Skin care - wound** **TEACH_3580** Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____

Current visit date

Date intervention initiated
Date eval ended

Intervention: **Infection control** **TEACH_2540** Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____

Current visit date

Date intervention initiated
Date eval ended

Intervention: **Give ed. materials** **TEACH_2220** Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____

Current visit date

Date intervention initiated
Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 4

Problem/DX: **Knowledge deficit, dressing change**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Dressing change** SKILL_1760

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: **Dressing change - pt** TEACH -3211

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 4

Problem/DX: **Knowledge deficit - milk drain**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Milk drain** EVAL **1735**

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 4

Problem/DX: **Knowledge deficit - empty drain**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Empty drain** EVAL **1733**

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 4

Problem/DX: **Knowledge deficit - record drainage**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Record drainage** EVAL **1738** Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 4

Problem/DX: **Knowledge deficit - lymphedema**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Lymphedema prevention** TEACH_2725

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: **Give educational material** TEACH_2220

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: **Lymphedema knowledge** EVAL_2727

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 4

Problem/DX: **Knowledge deficit - Breast self exam**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Self breast exam** **TEACH_1207** Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____
Date intervention initiated

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

1. Ineffective and ended
2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 4

Problem/DX: **Knowledge deficit - Range of motion**

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Range of motion, arm** DEMO_9020

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: **EX/Range of motion** TEACH_1870

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: **Functional level, arm** EVAL_2190

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: **Give ed. materials** TEACH_2220

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

Intervention: **Exercise/ROM** EVAL_1840

Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date intervention initiated Date eval ended

1st Evaluation

1. Intervention appears effective & continues
2. Intervention ineffective and ended
3. Single time intervention, eg., teaching, literature, demo
4. Non-compliant
5. 1st use and will evaluate next visit

Stop Evals

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2. Effective and completed
3. Intervention effective, Dx resolved
4. After initial use, patient non-compliant

INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # 4

Problem/DX: Consultation - report to doctor

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

Goal: (see guide) _____ Was goal met? ☐ Yes ☐ No

Problem Status: ☐ Complete response ☐ Partial response ☐ Symptom stable/acceptable
☐ Symptom stable/unacceptable ☐ Worsened

Status Date: (visit date): _____

Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

Intervention: **Final care report to surgeon** **REPORT_8000** Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

Intervention: (see guide) _____ # _____ Date entered: _____

1st Evaluation _____ On _____ Stop Evaluation _____ On _____
Current visit date Date eval ended

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Current visit date Date eval ended

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m

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Problem/DX: _____

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

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Evaluation: (see guide) _____

ALL INTERVENTIONS FOR THIS PROBLEM

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Problem/DX: _____

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3. Intervention effective, Dx resolved
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INTERVENTION AND PROBLEM STATUS

Enter all patient problems and corresponding interventions - see Guidelines

| | | | | |
|------------|-----------|---------------------|-------------|-------------------|
| Name _____ | ID# _____ | Date ____/____/____ | Log # _____ | Encounter # _____ |
|------------|-----------|---------------------|-------------|-------------------|

Problem/DX: _____

Ca Related? ☐ Yes ☐ No

ICD Code: (automatic fill in)

Entry Date: (Date problem first noted) _____ Goal Target Date: (see guidelines) _____ days

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Enter all patient problems and corresponding interventions - see Guidelines

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Problem/DX: _____

Ca Related? ☐ Yes ☐ No

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Stop Evals

1. Ineffective and ended
2. Effective and completed
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4. After initial use, patient non-compliant

ENCOUNTER SCREEN and TIME KEEPING

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

NEXT SCHEDULED ENCOUNTER DATE: _____ as a ☐ Home visit ☐ Phone Call

Current encoun. - Site: ☐ Home ☐ Phone

CPT (fills in automatically _____) **Problem Severity:** fills in automatically _____

TIME KEEPING

Direct care (time in minutes) _____ **Record Keeping:** (time in minutes) _____

Coordination of Care: consultations, referrals,(time in minutes) _____

Note: (fill in comments as needed - Example: Record Keeping time reflects time to learn program)

Date ____/____/____ Log # _____ Encounter # _____

NEXT SCHEDULED ENCOUNTER DATE: _____ as a ☐ Home visit ☐ Phone Call

Current encoun. - Site: ☐ Home ☐ Phone

CPT (fills in automatically _____) **Problem Severity:** fills in automatically _____

TIME KEEPING

Direct care (time in minutes) _____ **Record Keeping:** (time in minutes) _____

Coordination of Care: consultations, referrals,(time in minutes) _____

Note: (fill in comments as needed - Example: Record Keeping time reflects time to learn program)

Date ____/____/____ Log # _____ Encounter # _____

NEXT SCHEDULED ENCOUNTER DATE: _____ as a ☐ Home visit ☐ Phone Call

Current encoun. - Site: ☐ Home ☐ Phone

CPT (fills in automatically _____) **Problem Severity:** fills in automatically _____

TIME KEEPING

Direct care (time in minutes) _____ **Record Keeping:** (time in minutes) _____

Coordination of Care: consultations, referrals,(time in minutes) _____

Note: (fill in comments as needed - Example: Record Keeping time reflects time to learn program)

ENCOUNTER SCREEN and TIME KEEPING

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

NEXT SCHEDULED ENCOUNTER DATE: _____ as a ☐ Home visit ☐ Phone Call

Current encoun. - Site: ☐ Home ☐ Phone

CPT (fills in automatically _____) **Problem Severity:** fills in automatically _____

TIME KEEPING

Direct care (time in minutes) _____ **Record Keeping:** (time in minutes) _____

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Note: (fill in comments as needed - Example: Record Keeping time reflects time to learn program)

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Current encoun. - Site: ☐ Home ☐ Phone

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Direct care (time in minutes) _____ **Record Keeping:** (time in minutes) _____

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NEXT SCHEDULED ENCOUNTER DATE: _____ as a ☐ Home visit ☐ Phone Call

Current encoun. - Site: ☐ Home ☐ Phone

CPT (fills in automatically _____) **Problem Severity:** fills in automatically _____

TIME KEEPING

Direct care (time in minutes) _____ **Record Keeping:** (time in minutes) _____

Coordination of Care: consultations, referrals,(time in minutes) _____

Note: (fill in comments as needed - Example: Record Keeping time reflects time to learn program)

REFERRALS

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

SERVICE/COMMUNITY REFERRAL (last visit)

1. _____ Phone _____

2. _____ Phone _____

3. _____ Phone _____

Type of referral: ☐ Community (free) ☐ Service (professional)

Problem:

Reason for referral: (Example: Support Group)

p. 2. does not need to be completed

PHYSICIAN CONSULTATION

Name _____ ID# _____ Date ____/____/____ Log # _____ Encounter # _____

Surgeon week 1 report sent ____/____/____

Chart as problem with interventions/s with encounter that occurs closest to day 7 after surgery.

(See pages 7- 9 of guide)

Surgeon final report sent ____/____/____

Chart problem with intervention/s on day 14. (See pages 7 - 9 of guide.)

S & S seroma formation ____/____/____

Limitations arm ROM ____/____/____

S & S of infection ____/____/____

S & S of lymphedema ____/____/____

SUMMARIES

Patient name: _____ **ID#** _____

Date Nurse Visits Began: ____/____/____ **Date Ended:** ____/____/____ **No. of Encounters:** _____

Medical DX: (fill in Breast Cancer)

Problems Resolved: (list all resolved problems)

Nursing Interventions: (List all nursing interventions used throughout care)

Open Problems Remaining: (List all unresolved problems)

SERVICES SUMMARY

Services Used: (list all services used, i.e. nursing, social worker, etc.)

Other Community Resources: (list all referred resources, i.e. support groups)

Disposition Care Plan: (Example: Patient informed that this is last nurse visit. Referred to surgeon and primary physician for follow-up care)

Nurse intervenor: (type in nurse name)

Phone: (fills in automatically)

Agency (fills in automatically)

Fax: (fills in automatically)

Street: (fills in automatically)

City/ST/Zip (fills in automatically)



A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

NURSE CHARTING COMPUTER GUIDE

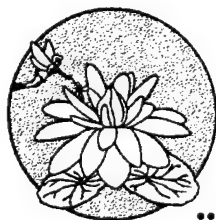
Appendix M

Nursing Care for Breast Cancer

***Nursing Guide to Patient Chart
Computer Documentation and Data Entry Program***

***Overviews,
Problem Statements,
Interventions***

| Topic | Page |
|--|-------------|
| Anxiety | 1 |
| Constipation | 4 |
| Consultation | 7 |
| Depression | 10 |
| Diarrhea | 13 |
| Fatigue | 16 |
| Fever | 19 |
| Incision | 22 |
| Insomnia | 25 |
| Nausea | 28 |
| Pain | 31 |
| Quality of Life | 34 |
| Education : ROM, fine motor ability, sensation, lymphedema, BSE . . | 37 |



...A New Beginning

ANXIETY - OVERVIEW

DEFINITION: A state or feeling of apprehension, uneasiness, agitation, uncertainty, and fear resulting from the anticipation of some threat or danger. Document relevant autonomic indicators, mood responses, motor responses, and hyperactivity indicators.

NURSING ACTIVITIES:

1. Encourage patient to vent her thoughts and feelings through talking, journal writing, exercise, or music.
2. Encourage the patient to utilize relaxation tapes, guided imagery, and/or relaxation exercises.
3. Encourage the patient to utilize coping mechanisms that have been effective in the past.
4. Assist the patient in learning new coping mechanisms, role play situations with the patient, teach anxiety interrupters: 1) look up, 2) control breathing, 3) lower shoulders, 4) slow thoughts, 5) alter voice, 6) give self directions, 7) imagine watching the situation from a distance.
5. Teach patient about the importance of maintaining a lifestyle that balances diet, exercise and rest.
6. Discuss unmet needs that may contribute to anxiety.
7. Provide information about the course of the disease and treatment to limit threat of the unknown.
8. Use diversional activities, such as magazines, radio, and/or television.
9. Provide the opportunity to explore cultural/religious aspects of responses to illness, loss, or death.
10. Encourage patient's active participation in treatment planning process.
11. Assess for presence of unrelieved pain, attempt to relieve or reduce to a level acceptable to the patient.
12. Refer to physician for the initiation of anxiolytic medication and/or supportive psychotherapy, or psycho educational therapy, if nursing interventions are not efficacious in reducing the patient's anxiety.

EXPECTED OUTCOMES:

1. Patient reports decreased level or absence of anxiety (refer to self-rating scale under assessment section).
2. Patient is able to state two methods of channeling energy constructively.
3. Patient is able to state two coping mechanisms that are efficacious in reducing anxiety.
4. Patient is able to identify both formal and informal support networks.
5. Patient reports decreased occurrence or absence of biophysical and/or psychosocial responses to anxiety, e.g. absence of sweating, tachycardia.
6. Patient demonstrates the ability to discuss disease and prognosis accurately and devoid of biophysical or psychosocial responses to anxiety.

ANXIETY PROBLEMS

| | |
|---|--------|
| ICD Code for anxiety | 309.24 |
| ICD code for consultation - surgeon reports | V65.8 |
| ICD code for lack of knowledge | V62.3 |

Choose from the following list for Anxiety Problem statements:

| Problem statement (Nsg Dx) | Problem Code |
|---|--------------|
| 1. Anger | 1060 |
| *2. Anxiety | 1080 |
| 3. Body image disturb | 1100 |
| 4. Coping, ineff d/t alter function | 1600 |
| 5. Coping ineff d/t disease | 1610 |
| 6. Coping ineff d/t other family member | 1620 |
| 7. Coping ineff d/t tx | 1630 |
| 8. Coping other | 1640 |
| 9. Decision making impaired | 1680 |
| 10. Decisional conflict | 1690 |
| 11. Fear | 1860 |
| 12. Grieving | 1900 |
| 13. Knowledge deficit, tx plan | 2260 |
| 14. Knowledge deficit - disease process, cancer | 2180 |
| 15. Role transition conflict | 2490 |
| 16. Sexual dysfunction | 2600 |
| 17. Spiritual distress | 2730 |
| 18. Knowledge deficit health resources | 2200 |
| 19. Consultation - report to doctor | 1585 |

Goal Target in days = 1-14 days

Goal: anxiety will diminish to acceptable level, i.e., 3 or less on a 1-10 scale.

Example Evaluation Statements: Anxiety controlled (3 or below on 1-10 scale).
 Anxiety persistent at 8 on 1-10 scale.
 Anxiety decreasing, but remains at 4 on 1-10 scale.

ANXIETY INTERVENTIONS

Assess

| | |
|-----------------|-------------|
| *Anxiety | ASSES _1090 |
| Nutrition | ASSES _3010 |

Counsel

| | |
|---|-------------|
| Support re active listening | COUNS _1010 |
| Anxiety | COUNS _1100 |
| Decisional conflict | COUNS _1590 |
| Support re individual | COUNS _3694 |
| Support re situational crises | COUNS _3540 |
| Support re ego enhancement, self-esteem | COUNS _1800 |
| Support re coping enhancement | COUNS _1520 |
| Support re lifestyle changes | COUNS _2690 |
| Support re problem solving/decision making | COUNS _3290 |
| Support re anticipatory guidance, expectations | COUNS _1080 |
| Support re hope instillation | COUNS _2400 |
| Support re spiritual | COUNS _3660 |
| Support re mutual goal setting | COUNS _2930 |

Prescribe

| | |
|-------------------------------|-------------|
| Exercise | PRESC _1878 |
| Bibliotherapy | PRESC _1157 |
| Music therapy | PRESC _2920 |
| Decision making support | PRESC _1585 |
| Alternative therapy | PRESC _3728 |
| Massage/back rub | PRESC _2730 |
| Relaxation | PRESC _3410 |
| Guided imagery | PRESC _2464 |
| Meditation | PRESC _2878 |
| Massage/back rub | PRESC _2735 |
| Energy management | PRESC _1818 |

Teach

| | |
|--|-------------|
| Exercise therapy - general | TEACH _1874 |
| Coping skills | TEACH _1540 |
| *Anxiety management | TEACH _1115 |
| Alternative therapy | TEACH _1030 |
| Relaxation techniques | TEACH _3420 |
| Humor | TEACH _2450 |
| Meditation | TEACH _2880 |
| Guided imagery | TEACH _2660 |
| Nutrition | TEACH _3020 |
| Disease process diagnosis | TEACH _1700 |
| Disease process diagnosis/non-cancer | TEACH _1710 |
| Treatment options and choices | TEACH _3790 |
| Treatment non-cancer | TEACH _3860 |
| Distraction | TEACH _1730 |

Skill

| | |
|----------------------|-------------|
| Guided Imagery | SKILL _2250 |
|----------------------|-------------|

Refer

| | |
|-----------------|-------------|
| Spiritual | REFER _5345 |
| Physician | REFER _3218 |

Evaluate

| | |
|---------------------------|------------|
| *Anxiety management | EVAL _1110 |
| Alternative therapy | EVAL _1040 |
| Bibliotherapy | EVAL _1154 |
| Relaxation | EVAL _3405 |
| Meditation | EVAL _2874 |
| Guided imagery | EVAL _2240 |
| Nutritional status | EVAL _3030 |

CONSTIPATION - OVERVIEW

DEFINITION: Difficulty in passing stools or an incomplete or infrequent passage of hard stools.

NURSING ACTIVITIES:

1. Identify and discuss with patient suspected etiologies/risk factors of constipation.
2. Discuss and teach dietary measures to prevent constipation:
 - 1) Fluid intake of 2-3 liters/day unless contraindicated
 - 2) High fiber intake (raw fruits, vegetables with skins, whole grains, bran, raisins, dates, prunes, prune juice).
 - 3) Warm hot drink (coffee, tea, or water with lemon juice) ½ hour before usual defecation.
3. Discuss and teach routines to promote elimination:
 - 1) Privacy, comfortable position
 - 2) Maintenance of a usual time schedule for BM's
 - 3) Regular exercise - walking, abdominal muscle strengthening
4. Initiate medications for constipation prevention or treatment in consultation or collaborative agreement with attending physician:
 - 1) Mild constipation, or low dose analgesics - stool softener (with laxative for narcotics)
Docusate sodium (Colace) 1-2 tabs (50 mg) up to TID
Docusate calcium (Doxidan, Surfak) 240 mg tab 1 QD
Docusate potassium (Dialose) 100 mg tabs 1-3 QD
Pericolace 1 QD
Docusate sodium 50 mg & 187 mg senna (Senekot) QD
Bulk forming agent if NOT on narcotics - psyllium varies with preparation from 1T to 1 packet 1-3 x/day.
 - 2) Moderate constipation (no stool in 3 days) - Milk of Magnesia 1-2 oz followed by glass of water at HS
Pericolace 1 BID-TID
Senekot S - 1 BID to 2 tabs TID and/or Theravac enema Q 3 days if no BM and/or Citrate of Magnesium Q 2-3 days
5. Impaction management should include hydration, and manual removal if not contraindicated by neutropenia or thrombocytopenia.
 - 1) Oil retention, tap water, milk & molasses (8 oz milk to 4 oz molasses warmed to body temp) or hypertonic phosphate enema (Fleets) to soften and loosen stool.
 - 2) Follow by manual disimpaction
 - 3) Implement medications appropriate to level of constipation present.
6. Teach patient signs and symptoms re constipation with require immediate reporting:
 - 1) Sudden onset, new or altered pattern (n patient with existing abdominal pain) of abdominal pain
 - 2) Distended abdomen
 - 3) Constipation unrelieved by current measures
 - 4) Fever >101
 - 5) Nausea and vomiting
 - 6) Bloody or tarry stools
7. When to notify the health care provider:
 - 1) Sudden onset, new or altered pattern (in patient with existing abdominal pain) of abdominal pain
 - 2) Distended abdomen
 - 3) Constipation unrelieved by current measures
 - 4) Fever >101
 - 5) Nausea and vomiting
 - 6) Bloody or tarry stools
 - 7) Any suspect bowel obstruction, acute abdomen, moderate to severe dehydration, or infection
 - 8) Adverse reactions to medications or measures used to treat constipation.

EXPECTED OUTCOMES:

1. Patient will identify factors that contribute to or cause constipation
2. Patient will identify and use measures to prevent or reduce constipation.
3. Resumption of usual bowel pattern (at least 3 stools per week).
4. Patient will identify signs and symptoms of complications related to constipation that require immediate medical attention.

CONSTIPATION PROBLEMS

| | |
|---|-------|
| ICD Code for constipation | 564.0 |
| ICD code for consultation - surgeon reports | V62.8 |
| ICD code for lack of knowledge | V62.3 |

Choose from the following list for Constipation Problem statements.

| Problem Statement (Nsg Dx) | Problem Code |
|--|--------------|
| 1. Constipation | 1580 |
| 2. Diarrhea | 1740 |
| 3. Nausea | 2330 |
| 4. Anorexia, side effects | 1070 |
| 5. Knowledge deficit meds, gen | 2230 |
| 6. Weight loss | 2880 |
| 7. Consultation - report to doctor | 1585 |

Goal Target in Days =3-4 days

Goal: Patient will report resumption of usual bowel pattern (at least 3 stools per week).

Example evaluation statements: Patient reports having no bowel movements in the past two days.
 Patient reports one soft stool on 06-01-97 after taking colace on 05-31-97.

CONSTIPATION INTERVENTIONS

Assess

*Constipation ASSES _1460

Prescribe

Constipation/impaction

management PRESC _1500

Alter medicines PRESC _2860

Treatment non-cancer PRESC _3785

OTC medications PRESC _3120

Teach

Disease process diagnosis

materials TEACH _1700

Disease process diagnosis

non cancer TEACH _1710

*Medications TEACH _2850

Treatment (surgery) TEACH _3830

Constipation TEACH _1490

Nutrition TEACH _3020

Bowel management

(constipation/diarrhea) . TEACH _1490

Exercise therapy - general . TEACH _1874

Prevention of complications TEACH _3280

Self-care constipation TEACH _1495

Skill

Enema SKILL _1810

*Evaluate

Constipation EVAL _1470

Monitor

Constipation MONIT _1480

Consult

With health care

provider CONSUL _2310 or _2300

CONSULTATION - SURGEON REPORTS OVERVIEW

Definition: Reports sent to surgeon approximately days 7 and day 14 post-operatively. This report is a standard study form, which is then individualized by the nurse to reflect each patient's post-surgical progress. The day 7 report is a progress report, and the day 14 report is the final report, as well as, notification that the patient has completed the study protocol, and not longer under our study's care.

Nursing Activities: Nurse will submit standardized study form to surgeon, which is individualized to patient's progress on about days 7 and 14 post-op.

Expected Outcomes:

1. Report 1 will be mailed to surgeon by day 7 post-op.
2. Report 2 will be mailed to surgeon by day 14 post-op.

CONSULTATION - SURGEON REPORTS PROBLEMS

ICD code Consultation - surgeon reports V65.8

Choose from following list for Consultation - Surgeon Reports problems

| Problem statement (Nsg Dx) | Problem code |
|---|--------------|
| 1. Consultation - Reports to doctor | 1585 |

Goal Target in days: 7 and 14

Goal: Each report will be sent on schedule

Example Evaluation Statements: 7 day surgeon progress report mailed on day 7 post op
14 day surgeon progress report mailed on day 14 post op.
Day 7 report delayed due to ----, sent on day 10.
Day 14 report delayed due to ----, sent on day 15.

CONSULTATION - SURGEON REPORTS INTERVENTIONS

Report

S & S seroma formation to surgeon REPORT _8040
Limitations arm ROM REPORT _8030
S & S of infection REPORT _8010
S & S of lymphedema REPORT _8020
Week 1 care report to surgeon REPORT _8050
Final care report to surgeon REPORT _8000

Refer

Physician REFER _3218

DEPRESSION - OVERVIEW

DEFINITION:

A mood disturbance characterized by feelings of sadness, despair, and discouragement resulting from and normally proportionate to some personal loss or tragedy. Document relevant symptom categories: Criteria A: Depressed mood most of the day, nearly every day (e.g. feels sad/empty or appears tearful). Criteria B: Weight loss/gain, insomnia/hypersomnia, psychomotor agitation/retardation, fatigue, low self-esteem, impaired concentration, suicidal ideation.

NURSING ACTIVITIES:

1. Encourage patient to vent her feelings verbally, through journal writing or creative expression.
2. Encourage active participation in treatment planning and identify opportunity for control.
3. Foster communication between patient, family and health team.
4. Assist patient and family to redefine goals, values, and view of self in terms of the reality of the disease, treatment, and resources.
5. Initiate exercise program if not contraindicated.
6. Encourage patient to identify and engage or increase pleasurable activity.
7. Initiate antidepressant therapy in consultation with attending physician. Refer as needed to psychiatrist for initiation/management of antidepressant therapy and/or psychotherapy.

EXPECTED OUTCOMES:

1. Patient denies depressed mood, demonstrates euthymia with mood congruent effect.
2. Patient reports resumption of appetite, and stabilization of weight.
3. Patient reports at least six consecutive hours of nocturnal sleep for five consecutive nights.
4. Patient reports resumption of baseline energy levels with decreased daytime fatigue.
5. Patient reports positive self-concept.
6. Patient denies feelings of helplessness, hopelessness.
7. Patient reports ability to concentrate with increased ability to make decisions.
8. Patient denies suicidal ideation and/or plan.
9. Patient is able to identify personal, family, community, and professional resources to meet crises of cancer experience or depressed state.

DEPRESSION PROBLEMS

| | |
|---|-------|
| ICD Code for depression | 296.2 |
| ICD code for consultation - surgeon reports | V65.8 |
| ICD code for lack of knowledge | V62.3 |

Choose from the following list for Depression Problem statements:

| Problem statements (Nsg Dx) | Problem Codes | Problem statements (Nsg Dx) | Problem Codes |
|--|---------------|---|---------------|
| 1. Depression | 1710 | 18. Grieving, anticipatory | 1910 |
| 2. Hopelessness | 1950 | 19. Grieving, dysfunctional | 1920 |
| 3. Coping, ineffective d/t disease | 1610 | 20. Home maintenance/management | 1940 |
| 4. Coping, ineffective d/t tx | 1630 | 21. Knowledge deficit, meds, gen'l | 2230 |
| 5. Coping, ineffective d/t altered function .. | 1600 | 22. Powerlessness | 2460 |
| 6. Coping, ineffective d/t other fam. member | 1620 | 23. Self esteem deficit | 2570 |
| 7. Coping, other | 1640 | 24. Sexual dysfunction | 2600 |
| 8. Decisional conflict | 1690 | 25. Sleep disturbance, insomnia | 2680 |
| 9. Fear | 1860 | 26. Sleep disturbance, other | 2690 |
| 10. Activity deficit, diversional | 1010 | 27. Social interaction | 2700 |
| 11. CG physical health, impaired | 1360 | 28. Social isolation | 2710 |
| 12. Communication with HCP: pt ineffective | 1530 | 29. Social support, inadequate | 2710 |
| 13. Community referral - resource need ... | 1540 | 30. Spiritual distress | 2730 |
| 14. Confusion, acute | 1550 | 31. Violence at self, potential | 2840 |
| 15. Depression, side effects | 1720 | 32. Role performance altered | 2480 |
| 16. Financial inadequacy | 1880 | 33. Consultation - report to doctor | 1585 |
| 17. Grieving | 1900 | | |

Goal Target in days = 14

Goal: Patient denies depressed mood, demonstrates euthymia with mood congruent effect.

Example Evaluation Statement: Patient exhibits depressed mood r/t altered role performance.
Depression resolved.
Depression rated by pt as 3 on 0-10 scale.

DEPRESSION INTERVENTIONS

Assess

Depression ASSES _1600
 Body image ASSES _1180

Counsel

Support re active listening COUNS _1010
 Support re decisional conflict ... COUNS _1590
 Support re depression COUNS _1610
 Support re individual COUNS _3694
 Support re ego enhancement/self
 esteem COUNS _1800
 Support anticipatory guidance ... COUNS _1080
 Support re mutual goal COUNS _2930
 setting COUNS _2930
 Support communication enhancement
 among family COUNS _1990
 Support crisis intervention
 Situational crisis COUNS _3540
 Support discuss problem of care
 with patient COUNS _1680
 Support re body image
 enhancement COUNS _1190
 Support re spiritual COUNS _3660
 Support re lifestyle changes COUNS _2690
 Support re hope instillation COUNS _2400

Prescribe

Music therapy PRESC _2915
 Decision making support PRESC _1585
 Energy management PRESC _1818
 Massage/back rub PRESC _2730
 Relaxation PRESC _3410
 Alter medications PRESC _2860

Teach

Bibliotherapy TEACH _1160
 Coping skills TEACH _1540
 Family therapeutic
 communication TEACH _1980
 Health system utilization TEACH _2350
 Problem solving TEACH _3350
 Disease process diagnosis
 material TEACH _1700
 Treatment options and choices .. TEACH _3790
 Medical plan of care TEACH _2810
 Exercise therapy TEACH _1874
 Humor TEACH _2450
 Guided imagery TEACH _2260
 Distraction TEACH _1730

Refer

Counselor REFER _1545
 Spiritual REFER _5345
 Physician REFER _3218
 Support group REFER _5355

Evaluate

Depression EVAL _1615
 Body image EVAL _1195

Monitor

Depression MONIT _1625, _1630

Consult HCP

Plan of care alteration CONS _2320
 Medication changes CONS _2310

DIARRHEA -OVERVIEW

1. Identify and discuss with patient suspected etiology/risk factors of diarrhea.
2. Teach dietary measures to correct or minimize diarrhea.
 - 1) Fluid intake of 2-3 liters/day unless contraindicated.
 - a) Rehydration with clear liquids over first 12-24 hours
 - b) Use rehydration solutions such as Gatorade, Pedialyte, or half strength clear juice (apricot and peach).
 - c) Undiluted juices (apple, grape, cranberry) may exacerbate diarrhea due to high osmolality.
 - d) Avoid milk or milk products (except yogurt and buttermilk).
 - 2) Begin eating low residue diet or BRAT diet within 24 hours to prevent villous atrophy.
 - a) BRAT diet: bananas, rice, applesauce, toast
 - b) Low residue diet, high calorie, high protein: eggs, yogurt, buttermilk, fish, poultry, beef that's baked or roasted, rice, pudding, custards, cooked cereals, bananas, applesauce, white bread, crackers, noodles, baked, boiled, or mashed potatoes, cooked vegetables with little fiber.
 - c) Avoid: raw fruits, vegetables with skin and seeds, whole grain products, bran, popcorn, raisins, dates, prunes, prune juice, fried or greasy foods, gas forming foods (broccoli, cauliflower, beans), strong spices, caffeinated beverages and foods, alcohol.
3. Teach skin care measures:
 - 1) Gentle cleansing with mild soap (Dove, Ivory) and warm water after each BM.
 - 2) Apply moisture barrier (Desitin, A&D)
 - 3) Anusol cream for hemorrhoidal discomfort.
4. Initiate diagnostic evaluation of diarrhea as indicated in consultation with attending physician.
5. Initiate medications for diarrhea prevention or treatment in consultation with attending physician.
 - 1) Avoid antiperistaltic agents - they may prolong or worsen diarrhea associated with infectious causes.
 - 2) Loperamide (Immodium) 2 mg tabs. Initial dose 2 tabs followed by 1 after each diarrhea stool up to 8 per day.
 - 3) Diphenoxylate 2.5mg with atropine 0.025 mg (Lotomil) 1-2 tabs up to QID. Reduce dose when control achieved.
 - 4) Kaopectate 2-4 T Q 3-4 hrs for 1-2 days.
 - 5) Bismuth Subsalicylate 2 T Q 30 minutes, up to 8 doses or QID
 - 6) Psyllium 1T to 1 Packet.
6. Impaction management should include hydration, and manual removal if not contraindicated.
 - 1) Oil retention, tap water, milk & molasses (8 oz milk to 4 oz molasses warmed to body temp) or hypertonic phosphate enema (Fleets) to soften and loosen stool.
 - 2) Follow by manual disimpaction
 - 3) Implement medications appropriate to level of constipation present.
7. Teach patient signs and symptoms re diarrhea which require immediate reporting:
 - 1) Sudden onset, new or altered pattern (in patient with existing abdominal pain) of abdominal pain
 - 2) Diarrhea unrelieved by current measures
 - 3) Fever >101
 - 4) Nausea and vomiting
 - 5) Bloody or tarry stools
8. When to notify the health care provider:
 - 1) Sudden onset, new or altered pattern (in patient with existing abdominal pain) of abdominal pain
 - 2) Diarrhea unrelieved by current measures
 - 3) Fever >101
 - 4) Nausea and vomiting
 - 5) Bloody or tarry stools
 - 6) Anal fissure or thrombosed hemorrhoids
 - 7) Any suspect acute abdomen, moderate to severe dehydration, or infection

Expected Outcomes:

1. Patient will identify factors that contribute to or cause diarrhea.
2. Patient will identify and use measures to prevent or reduce diarrhea.
3. Patient will report maintenance or normalization of usual bowel pattern (at least 3/week, <4/day).
4. Patient will identify s/s of complications related to diarrhea that require immediate medical attention.
5. Patient will implement measure to prevent skin breakdown if appropriate.

DIARRHEA PROBLEMS

| | |
|---|-------|
| ICD codes for diarrhea | 558.9 |
| ICD code for consultation - surgeon reports | V65.8 |
| ICD code for lack of knowledge | V62.3 |

Choose from the following list for Diarrhea Problem statements.

| | Problem Statement (Nsg Dx) | Problem Code |
|----|---------------------------------------|--------------|
| 1. | Diarrhea | 1740 |
| 2. | Constipation | 1580 |
| 3. | Incontinence, bowel | 2040 |
| 4. | Knowledge deficit, meds, gen | 2230 |
| 5. | Knowledge deficit, tx plan | 2260 |
| 6. | Weight loss | 2880 |
| 7. | Consultation - report to doctor | 1585 |

Goal Target in days = 1-3

Goal : Diarrhea will subside within 3 days.

Example Evaluation Statements: Diarrhea has subsided
Diarrhea improving, no signs of dehydration
Diarrhea persists, surgeon notified

DIARRHEA INTERVENTIONS

Assess

Diarrhea ASSESS _1640

Prescribe

Diarrhea management PRESC _1660

OTC medications PRESC _3120

Alter medications PRESC _2860

Teach

Disease process diagnosis

 materials TEACH _1700

Disease process diagnosis

 non-cancer TEACH _1710

Medications TEACH _2850

Treatment (surgery) TEACH _3830

Diarrhea TEACH _1670

Nutrition TEACH _3020

Prevention of complications TEACH _3280

Constipation/impaction

 management TEACH _1490

Skill

Enema SKILL _1810

Evaluate

Diarrhea EVAL _1650

Nutrition EVAL _3015

Consult

Plan of care alterations CONS _2320

Nurse provides info CONS _2280

Nurse seeks info CONS _2290

FATIGUE - OVERVIEW

DEFINITION: An overwhelming sense of exhaustion and decreased capacity for physical and mental work regardless of adequate sleep. Defining characteristics are verbalization of fatigue or lack of energy and inability to maintain usual routines.

NURSING ACTIVITIES:

1. Identify and discuss with patient suspected etiology of fatigue, including but not limited to disease, medications that contribute to fatigue, comorbid conditions, and cancer treatments.
2. Assist patient in recognition of symptoms of fatigue.
 - 1) Explain differences between acute fatigue (tiredness) and chronic fatigue.
 - 2) Explain that fatigue is an expected side effect of treatment and that it usually resolves within a few weeks after surgery.
 - 3) Instruct patient to notify health care provider for increase in severity of fatigue.
 - 4) each patient that new onset, or changes in the manifestations of fatigue may signal complications and that they must be reported.
3. Identify and refer or treat underlying physical causes of fatigue associated with disease process, treatment or comorbidity, in consultation with attending physician.
4. Discuss and teach measures to decrease or manage fatigue:
 - 1) Rest/Activity/Lifestyle change - prioritization of ADL's, pacing activities, rest periods.
 - 2) Relaxation techniques to promote rest and sleep, adaptive coping, and pain relief.
 - 3) Initiate treatment for affective disorders associated with fatigue.
 - 4) Assist patient to manage their environment and utilize community resources to decrease demands upon time and energy.
 - 5) Reduce attentional fatigue and teach restorative techniques.

EXPECTED OUTCOMES:

1. Decrease fatigue to acceptable level as verbalized by patient.
2. Patient will identify factors that cause or contribute to fatigue.
3. Patient will identify and use measures to reduce fatigue and or restore energy.
4. Patient will maintain priority roles and functional status.
5. Patient will verbalize decreased or absence of distress associated with fatigue.

FATIGUE PROBLEMS

ICD Code for fatigue 780.7
ICD code for consultation - surgeon reports V65.8

Choose from the following list for Fatigue Problem statements:

| Problem Statements (Nsg Dx) | Problem Code |
|---|--------------|
| *1. Activity Intolerance (physical) | 1020 |
| 2. Anemia, side effects | 1050 |
| 3. Depression, side effects | 1710 |
| 4. Fatigue, acute | 1840 |
| 5. Sleep disturbance, insomnia | 2680 |
| 6. Sleep disturbance, other | 2690 |
| 7. Social interaction, impaired | 2700 |
| 8. Social support, inadequate | 2720 |
| 9. Weakness | 2860 |
| 10. Role performance, altered | 2480 |
| 11. Report to doctor | 1585 |

Goal Target in days = 1-14

Goal: Decrease fatigue to acceptable level as verbalized by patient.

Example Evaluation Statements: Fatigue persistent at 8 on 1-10 scale
Fatigue decreasing (2 on 1-10 scale)

FATIGUE INTERVENTIONS

Assess

*Fatigue ASSES _2000
 Sleep-rest pattern ASSES _3634

Counsel

Support active listening ... COUNS _1010
 Support anticipatory
 guidance COUNS _1080
 Support mobilize community
 resource COUNS _2910
 Support re family
 mobilization COUNS _1930
 Support re lifestyle changes COUNS _2690
 Support depression COUNS _1610
 Support anxiety management COUNS _1100
 Support re anger COUNS _1060
 Mobilize resources -
 caregiver COUNS _2900
 Support re problem solving/
 decision making ... COUNS _2900
 Support re decisional conflict COUNS _1590
 Support re mutual goal
 setting COUNS _2930

Prescribe

Energy management PRESC _1818
 Guided Imagery PRESC _2464
 Relaxation PRESC _3410
 Music therapy PRESC _2920
 Environmental comfort PRESC _1825

Teach

Disease process diagnosis
 materials TEACH _1700
 Disease process diagnosis
 non-cancer TEACH _1710

Teach, continued

Medications TEACH _2850
 Treatment (surgery) TEACH _3830
 Fatigue TEACH _2030
 Energy conservation TEACH _1814
 Self-monitoring of symptom
 control TEACH _3710
 Exercise therapy - general . TEACH _1874
 *Sleep/rest hygiene TEACH _3638
 Pain management -
 non-prescriptive ... TEACH _3180
 Pain management - prescrip TEACH _3190
 Guided imagery TEACH _2260
 Relaxation technique TEACH _3420
 Meditation TEACH _2880
 Music therapy TEACH _2920
 Coping skills TEACH _1540
 Anxiety management TEACH _1115
 Alternative therapies TEACH _1030

Skill

Guided Imagery SKILL _2250

Evaluate

*Fatigue EVAL _2010
 Guided Imagery EVAL _2240
 Anxiety management EVAL _1110
 Anger control EVAL _1070
 Alternative therapies EVAL _1040

Monitor

Fatigue MONIT _2020

Consult

Nurse provides info CONS _2280

FEVER - OVERVIEW

DEFINITION: 101F or over

NURSING ACTIVITIES:

1. Provide adequate hydration, as fluid and caloric demands are increased at elevated temperatures.
2. Contact the attending physician for possible initiation of antibiotic and/or anti-fungal therapy.
3. Prescribe nonsteroidal anti-inflammatory agents (indocin, naproxen) or acetaminophen.
4. During febrile episodes, remove excess clothing and linens, and provide tepid bathing/sponging. During periods of chills, replace wet blankets with warm, dry blankets, keep patient out of drafts, adjust ambient room temperature.

EXPECTED OUTCOME:

Patient's temperature will return to baseline.

FEVER PROBLEMS

| | |
|--|-------|
| ICD for fever | 780.6 |
| ICD for infection - post surgical | 998.5 |
| ICD for consultation - surgeon reports | V65.8 |
| ICD for lack of knowledge | V62.3 |

Choose from the following list for Fever Problem statements.

| | Problem Statements (Nsg Dx) | Problem Code |
|-----|---|--------------|
| 1. | Fever | 1870 |
| 2. | Infection, potential for | 2110 |
| 3. | Infection, skin | 2130 |
| 4. | Knowledge deficit, disease proc, non cancer | 2170 |
| 5. | Knowledge deficit, meds, gen | 2230 |
| 6. | Knowledge deficit, tx plan | 2260 |
| 7. | Knowledge deficit, S & S infection | 2222 |
| 8. | Weight loss | 2880 |
| 9. | Tachycardia, side effects | 2740 |
| 10. | Consultation - report to doctor | 1585 |

Goal Target in days = 1-3

Goal: Temperature less than 101 within 3 days

Example Evaluation Statements: Temperature within normal limits
 Infection suspected, referred to surgeon
 Hydration with in normal limits
 Temp decreasing toward normal with fluid increase,
 no S or S of infection.

FEVER INTERVENTIONS

Assess

Fever control ASSES _2040
Med effectiveness ASSES _2840
S&S of Infection ASSES _2520

Prescribe

OTC medication PRESC _3120
Environmental comfort PRESC _1825
Alternative med PRESC _2860
Infection control PRESC _2530

Teach

Disease process diagnosis
 material TEACH _17 00
Disease process diagnosis
 non-cancer TEACH _1710
Medication TEACH _2850
Prevention of complications TEACH _3280
Fever control TEACH _2070
Medical plan of care TEACH _2810
S & S infection -
 caregiver TEACH _1358

Evaluate

Fever control EVAL _2050
Med effectiveness EVAL _2840
Infection status EVAL _2550

Monitor

Fever control MONIT _2060
Meds need for alteration ... MONIT _2870
S/S infection MONIT _2556

Consult HCP

Nurse provides info CONS _2280
Nurse seeks info CONS _2290

Report

S & S infection to
 surgeon REPORT _8010

INCISION - OVERVIEW

DEFINITION: A cut produced surgically by a sharp instrument creating an opening into an organ or space in the body.

NURSING ACTIVITIES:

1. Make sure the patient has dressing supplies
2. Assess and reinforce patient skill re: dressing changes, emptying the drain, measuring drainage, milking tubing.
3. Examine incision and record location, approximation, when the dressing was last changed, and appearance/amount of drainage on the dressing. Report to surgeon if incision is not well approximated or s/s infection are present.
4. Assess and teach patient about signs and symptoms of infection.
5. Assess and document hematoma and seroma
6. Assess closed drainage: record amount, appearance, and consistency.
7. Assess for clogs in the tubing, and milk tubing until clots pass through to bulb.

EXPECTED OUTCOMES:

1. Patient will have adequate dressing supplies.
2. Patient or caregiver will demonstrate correct procedure for changing dressing.
3. Patient or caregiver will demonstrate correct procedure for emptying the drain.
4. Patient or caregiver will demonstrate correct procedure for measuring drainage.
5. Patient or caregiver will demonstrate correct procedure for milking tubing.
6. Tubing will remain free of clogs and will drain fluid properly.
7. Incision will be well-approximated.
8. Incision will be free of infection.

INCISION PROBLEMS

| | |
|---|-------|
| ICD code breast incision | 879.0 |
| ICD code for self-care deficit | V66.0 |
| ICD code consultation - surgeon reports | V65.8 |
| ICD for lack of knowledge | V62.3 |
| ICD for convalescence following surgery | V66.0 |

Choose from the following list for Incision Problem statements.

| Problem Statement (Nsg Dx) | Problem Code |
|---|--------------|
| *1. Knowledge deficit - milking drainage tube | 2144 |
| *2. Knowledge deficit - empty drain | 2184 |
| *3. Knowledge deficit - recording drainage | 218 |
| 4. Skin integrity, surgery | 2675 |
| 5. Knowledge deficit - dressing change | 2164 |
| 6. Consultation - report to doctor | 1585 |
| 7. Knowledge deficit r/t s/s symptoms of Seroma/hematoma formation | 2226 |
| 8. Knowledge deficit - community resources | 2148 |
| 9. Self-care deficit - measure drainage | 2533 |
| 10. Self - care deficit - clogged drainage tube | 2582 |
| 11. Self-care deficit - dressing change | 2542 |

Goal Target in days = 1-4

Goal: Incision will show close approximation without gapping, and without signs of infection. The patient or caregiver will be independent with the various aspects of incision care, i.e., dressing change, drainage tubing, emptying drain, recording drainage.

Example Evaluation Statements: Incision well approximated without redness or swelling. Pt or caregiver independent in incision care. Incision red and swollen, pt. Referred to surgeon for potential infection follow- up care.

INCISION INTERVENTIONS

Assess

Resource needs ASSES _3430
Skin integrity - wound ASSES _3630
Dressing change ability ASSES _1765
Seroma ASSES _3524
Milking drainage tube ASSES _1734
Empty drain ASSES _1731
Recording drainage ASSES _1738

Monitor

Empty drain MONIT _1711
Dressing change MONIT _1751

Prescribe

Dressings PRES _1770

Teach

Medical plan of care TEACH _2810
Prevention of
 complications TEACH _3280
*Skin care - wound TEACH _3580
Application/use
 OTC meds TEACH _3723
*Dressing change
 - patient TEACH _3211
Dressing change
 - caregiver TEACH _1352
*Infection control TEACH _2540
Seroma TEACH _3528
*Milking drainage
 tube - pt TEACH _3214

Teach, continued

Milking drainage
 tube - cg TEACH _1354
*Empty drain - patient TEACH _3213
Empty drain -
 care giver TEACH _1351
*Recording
 drainage - pt TEACH _3216
Recording
 drainage - cg TEACH _1356
CG Dressing change TEACH _1352

Skill

*Dressing change SKILL _1760
Incision care SKILL _2480
Nurse unclog drain SKILL _1737

Evaluate

Incision care EVAL _2490
Skin care - wound EVAL _3570
Dressing change EVAL _1745
*Milk drainage tube EVAL _1733
*Emptying drain EVAL _1731
*Recording drainage EVAL _1738

Report

Seroma to surgeon REPORT _8040

Procedure

Dressing change PROC _1750
Incision care PROC _2470

Demonstrate

Unclogging drainage
 tube DEMO _9010

INSOMNIA- OVERVIEW

DEFINITION: Inability to go to sleep, stay asleep, or sleep long enough to feel rested and relaxed upon awakening.

NURSING ACTIVITIES:

1. Instruct patient on measures to promote a restful sleep environment.
 - 1) Encourage use of usual clothing worn at bedtime such as gowns, pajamas, underwear, no clothing.
 - 2) Decrease or increase environmental stimuli such as lighting, music, and presence of significant other per client preference.
 - 3) Establish preferred room temperature.
 - 4) Avoid strenuous exercise 2 hours prior to bedtime.
 - 5) Decrease fluid intake prior to bedtime
2. Instruct patient on measures to increase relaxation before bedtime.
 - 1) Encourage bathing, snack and/or warm milk, back rub, positioning, reading or watching television, progressive muscle relaxation, or imagery.
 - 2) Modify diet to avoid heavy meals or intake of stimulants such as caffeine or alcohol before bedtime.
3. Teach patient measures to prevent impairment of sleep.
 - 1) Maintain daily routine to prevent impairment of sleep level by pacing to prevent fatigue.
 - 2) Begin routine of daily exercise (if tolerated).
 - 3) Avoid prolonged time periods in bed if not sleeping.
 - 4) Maintain regular retirement time at night and arousal time in morning to comply with circadian rhythm.
4. Discuss with patient complications to monitor related to insomnia.
5. Instruct patient on stress management techniques.
6. Instruct patient regarding symptoms to report to health care provider.
 - 1) Impairment of activities of daily living
 - 2) Presence of restlessness, increasing irritability, confusion, lethargy, increasing fatigue, apathy, decreased concentration and problem solving-ability.
 - 3) Increasing depression

EXPECTED OUTCOMES:

1. Patient will describe personal risk factors for insomnia.
2. Patient will participate in measures to minimize the risk of occurrence, severity, and complications of insomnia.
3. Patient will report signs, symptoms, and complications of insomnia to nurse or physician.
4. Patient will list changes that require professional assistance in management - i.e. insomnia that interferes with the patient's ability to function at desired level.

INSOMNIA PROBLEMS

| | |
|---|--------|
| ICD code for insomnia | 307.41 |
| ICD code for consultation - surgeon reports | V65.8 |

Choose from the following list for Insomnia Problem statements

| Problem Statement (Nsg Dx) | Problem Code |
|---|--------------|
| 1. Sleep disturbance, insomnia | 2680 |
| 2. Sleep disturbance, other | 2690 |
| 3. Anxiety | 1080 |
| 4. Coping other | 1640 |
| 5. Depression | 1710 |
| 6. Pain acute | 2380 |
| 7. Pain breakthrough | 2400 |
| 8. Pain, other | 2430 |
| 9. Spiritual distress | 2730 |
| 10. Consultation - report to doctor | 1585 |

Goal Target in days = 1-7

Goal: Insomnia improves to a satisfactory (3 or less on a 1-10 scale)

Example Evaluation Statements: Insomnia resolved.
Insomnia at a 3 or less.
Insomnia improving, but remains unacceptable to pt.

INSOMNIA INTERVENTIONS

Assess

| | |
|------------------|--------------|
| Insomnia | ASSESS _2590 |
| Anxiety | ASSESS _1090 |
| Depression | ASSESS _1600 |

Counsel

| | |
|------------------|-------------|
| Anxiety | COUNS _1100 |
| Depression | COUNS _1610 |

Prescribe

| | |
|-----------------------------|-------------|
| Bibliotherapy | PRESC _1157 |
| Relaxation | PRESC _3410 |
| Guided Imagery | PRESC _2464 |
| Environmental comfort | PRESC _1825 |
| Massage/back rub | PRESC _2730 |
| Music therapy | PRESC _2915 |
| Medication alteration | PRESC _2860 |
| OTC Meds | PRESC _3120 |
| Energy management | PRESC _1818 |

Teach

| | |
|---------------------------|-------------|
| Bibliotherapy | TEACH _1160 |
| Insomnia | TEACH _2620 |
| Alternative therapy | TEACH _1030 |
| Nutrition | TEACH _3020 |
| Medication | TEACH _2850 |

Teach, continued

| | |
|-----------------------------|-------------|
| Self-monitoring of symptom | |
| control | TEACH _3698 |
| Prevention of complications | TEACH _3280 |
| Anxiety management | TEACH _1115 |
| Depression management .. | TEACH _1635 |

Evaluate

| | |
|-------------------------------|------------|
| Insomnia | EVAL _2600 |
| Alternative therapy | EVAL _1040 |
| Medication effectiveness | EVAL _2840 |
| Anxiety management | EVAL _1110 |
| Depression | EVAL _1620 |

Monitor

| | |
|------------------------------|-------------|
| Insomnia | MONIT _2610 |
| Medication need to alter ... | MONIT _2870 |
| Depression | MONIT _1630 |

NAUSEA - OVERVIEW

DEFINITION: A sensation often leading to the urge TO vomit

NURSING ACTIVITIES:

1. Identify and discuss with patient suspected etiology of nausea and vomiting.
2. Identify and refer or treat underlying physical causes of nausea and vomiting associated with disease process, treatment or comorbidity, in consultation with attending physician.
 - 1) Obstruction - refer all patients with suspected obstruction to attending physician.
 - 2) Gastrointestinal ulceration or bleeding - refer to attending physician.
 - 3) Central nervous system pathology - refer to attending physician
 - 4) Electrolyte imbalance - refer to attending physician.
 - 5) Nausea with localizing moderate to severe abdominal tenderness or fever - refer to attending physician
3. Initiate antiemetics based upon the suspected cause of nausea and vomiting in consultation with attending physician:
 - 1) Prochlorperizine (Compazine) 5-10 mg po or IM q 4-6 hr prn.
 - 2) Prochlorperizine (Compazine) suppositories 10-20 mg 1 po q 12 hrs for nausea (usually ATC for low levels of continuous nausea).
 - 3) Promethazine (Phenergan) 12.5-25 mg po q 8-12 hrs, available as suppositories 25 mg and syrup 25 mg/5 ml for gastroenteritis.
4. Discuss and teach measures to decrease stimuli of nausea and vomiting.
 - 1) Reduce unpleasant noise, odors, sights
 - 2) Decrease unnecessary motion
 - 3) Provide for ventilation and cool environment
 - 4) Modify diet to include cool, bland foods
 - 5) Oral care prior to eating particularly if nausea associated with taste alterations
5. Teach patient ways to minimize complications of nausea and vomiting.
 - 1) Replace fluids lost with high calorie, electrolyte rich cool liquids (Gatorade, popsicles, soft drinks)
 - 2) Assess for dehydration and report
6. Discuss and teach relevant nonpharmacological approaches to control nausea and vomiting.
7. Initiate bowel regimen for nausea caused by constipation or impaction (or evaluate and adjust as needed):
 - 1) Do NOT administer laxative or enemas to patient with concurrent fever and/or symptoms suggestive of acute abdomen
 - 2) Mild constipation: Colace or Pericolace 1 tab BID to TID, and/or stress need for adequate fluids and fiber
 - 3) Moderate constipation (no stool in 3 days): Milk of Magnesia 1-2 oz followed by a glass of water, Pericolace BID-TID, or Dulcolox tabs/suppositories as needed.
 - 4) Severe constipation (high dose opioid or bedridden):
 - a) Pericolace TID
 - b) Senikot BID to 2 tabs TID
 - c) Theravac enema q 3 days if no BM
 - d) Citrate of magnesium q 2-3 days
 - e) For impaction - oil retention or milk and molasses enema
8. Teach patient when to notify health care provider:
 - 1) New or worsening or uncontrolled nausea and vomiting
 - 2) Weight loss greater than 10% of body weight
 - 3) Presence of signs/symptoms of dehydration or gastrointestinal bleeding.

EXPECTED OUTCOMES:

1. Decrease nausea to acceptable level, and alleviate any vomiting
2. Patient will report signs, symptoms, and complications to the attending physician.
3. Patient will prevent/avoid sequelae of prolonged nausea and vomiting.
4. Identify and use measures to reduce nausea and vomiting.
5. Identify contributing factors to onset of nausea and/or vomiting.

NAUSEA PROBLEMS

| | |
|---|-------|
| ICD code for nausea | 787.0 |
| IDC code for consultation - surgeon reports | V65.8 |
| IDC code for Knowledge deficit | V62.3 |

Choose from the following list for Nausea Problem statements.

| Problem Statement (Nsg Dx) | | Problem Code |
|----------------------------|---|--------------|
| 1. | Nausea | 2330 |
| 2. | Vomiting | 2850 |
| 3. | Constipation | 1580 |
| 4. | Knowledge deficit , meds, general | 2230 |
| 5. | Consultation - report to doctor | 1585 |

Goal Target in days = 1-2

Goal: Nausea will subside with in 2 days.

Example Evaluation Statements: Nausea resolved.
Nausea improving as constipation resolves.
Nausea persistent, referred to surgeon.

NAUSEA INTERVENTIONS

Assess

Nausea ASSES _2940
Med effectiveness ASSES _2830

Prescribe

Alter medications PRESC _2860
OTC medications PRESC _3120
Environmental comfort PRESC _1825
Imagery PRESC _2464
Relaxation PRESC _3410
OTC medications PRESC _3120
Music therapy PRESC _2915

Teach

Disease process diagnosis
 material TEACH _1700
Disease process diagnosis
 non-cancer TEACH _1710
Medications TEACH _2850
Treatment (surgery) TEACH _3830
Self-monitoring of symptom
 control TEACH _3698
Nausea TEACH _2970
Give educational materials . TEACH _2220
Nutrition TEACH _3020
Oral care TEACH _3060
Relaxation TEACH _3420
Guided imagery TEACH _2260
Meditation TEACH _2880

Teach, continued

Distraction TEACH _1730
Prevention of complications TEACH _3280
Constipation Bowel
 Management TEACH 1490

Refer

Counselor COUNS _1545

Evaluate

Nausea EVAL _2950
Med effectiveness EVAL _2840

Monitor

Nausea MONIT _2960

Consult HCP

Nurse provides info CONS _2280
Nurse seeks info CONS _2290

PAIN - OVERVIEW

DEFINITION: An unpleasant sensation caused by noxious stimulation of the sensory nerve endings.

NURSING ACTIVITIES:

1. Identify and discuss with patient suspected etiology of pain.
2. Instruct patient in use of pain rating scale.
3. Instruct patient regarding:
 - 1) Pain medication regimen
 - 2) Utilize pain diary to reevaluate effectiveness of interventions
 - 3) When to notify HCP and what to tell HCP about the pain
4. Discuss and teach relevant nonpharmacological comfort measures:
 - 1) Cognitive behavioral: spiritual, emotional, educational interventions
 - 2) Relaxation techniques: guided imagery, progressive relaxation, meditation
 - 3) Distraction: humor, music therapy
 - 4) Physical modalities: massage, exercise, cold/heat
5. Initiate analgesic based on World Health Organization analgesic ladder steps and consultation with attending physician:
 - 1) Step 1: Patient who presents with mild to moderate pain would be treated with a non-opioid analgesic combined with an adjuvant analgesic if a specific indication for one exists
 - 2) Step 2: Patient whose pain is not relieved by first step regimen or who present with moderate to severe pain should be treated with an oral opioid for moderate pain combined with a non-opioid analgesic as well as an adjuvant analgesic, if a specific indication for one exists. In treating continuous pain, analgesics should be given on a regular basis "by the clock" so the next dose is given before the effect of the previous one wears off.
 - 3) Step 3: Patients whose pain is not relieved by the second step or who present with very severe pain should be treated with an opioid for severe pain with or without a non-opioid analgesic for with an adjuvant analgesic. In treating continuous pain, analgesics should be given on a regular basis, "by the clock".
6. Use analgesic with short half life on an "as needed" or "breakthrough dose" for intermittent pain that can occur spontaneously or in relation to a specific activity.
7. Increase current dosage of analgesic when appropriate using AHCPR guidelines for acute/chronic pain in consultation or collaborative agreement with attending physician.
8. Initiate adjuvant drugs to enhance analgesic efficacy, treat concurrent symptoms, and provide independent analgesia for specific types of pain in consultation or collaborative agreement with attending physician: corticosteroids, anticonvulsants, antidepressants, neuroleptics, hydroxyzine, psychostimulants.
9. Initiate bowel regimen for constipation - see constipation guidelines.
10. When to notify the health care provider:
 - 1) Pain unrelieved by present medications
 - 2) Patient unarousable or confused
 - 3) Patient level of alertness changed
 - 4) Constipation unrelieved by bowel regimen, urinary retention or vomiting
 - 5) Respiration depressed (8 or below)
 - 6) No food or fluid intake for 24 hours
 - 7) Temperature >101 F.

EXPECTED OUTCOMES:

1. Decrease pain to acceptable level as verbalized by patient.
2. Avoid or control pain medication side effects.
3. Patient will verbalize medication regimen.

PAIN PROBLEMS

ICD Code for pain 611.71

ICD Code for consultation - surgeon reports V65.8

ICD code for Knowledge deficit V62.3

Choose from the following list for Pain Problem statements

| Problem statements (Nsg Dx) | Problem Code |
|--|--------------|
| *1. Pain, acute | 2380 |
| 2. Pain, other | 2430 |
| 3. Pain, break through | 2400 |
| 4. Knowledge deficit, biologics | 2150 |
| 5. Knowledge deficit, surgery | 2250 |
| 6. Knowledge deficit, treatment plan | 2260 |
| 7. Knowledge deficit, meds, general | 2230 |
| 8. Knowledge deficit, health resources | 2200 |
| 9. Fear | 1860 |
| 10. Activity deficit, diversional | 1010 |
| 11. Anger | 1060 |
| 12. Anxiety | 1080 |
| 13. Community referral-resource need | 1540 |
| 14. Coping, ineffective D/T disease | 1610 |
| 15. Mobility, impaired other | 2300 |
| 16. Consultation - report to doctor | 1585 |

Goal Target in days = 1-14

Goal: Pain will diminish to acceptable level , i.e., 3 or less on a 1-10 scale.

Example Evaluation Statements: Pain persistent at 8 on 1-10 scale
 Pain controlled (3 or below on 1-10 scale)

PAIN INTERVENTIONS

Assess

*Pain control ASSES _3140

Counsel

Support re anticipatory guidance COUNS _1080

Spiritual concerns COUNS _3660

Support group COUNS _3690

Support hope instillation COUNS _2400

Prescribe

Guided Imagery PRESC _2464

Relaxation PRESC _3410

Music therapy PRESC _2915

Massage/back rub PRESC _2730

Cold therapy PRESC _1430

Heat therapy PRESC _2360

Heat /cold therapy PRESC _2375

Pain management - prescriptive . PRESC _3190

Pain mgmt. - non-prescriptive .. PRESC _3180

Alter medications PRESC _2860

*OTC medications PRESC _3120

Teach

Disease process diagnosis TEACH _1700

Disease process diagnosis

 non-cancer TEACH _1710

*Medication TEACH _2850

Treatment (surgery) TEACH _3830

Self-monitoring of symptom

 control TEACH _3698

Teach, continued

Give educational materials TEACH _2220

Guided imagery TEACH _2260

Relaxation technique TEACH _3420

Meditation TEACH _2880

Distraction TEACH _1730

Humor TEACH _2450

Exercise, general TEACH _1874

Medication - OTC meds TEACH _2871

Medication - OTC application .. TEACH _2872

Medication - prescription meds .. TEACH _2875

Prevention of complications TEACH _3280

Constipation, bowel management TEACH _1490

Refer

Counselor REFER _5070

Spiritual REFER _5345

Support group REFER _5355

*Evaluate

Pain control EVAL _3150

Monitor

Pain control MONIT _3160

QUALITY OF LIFE - OVERVIEW

DEFINITION: The patient's opinion about how illness or change in lifestyle affects his/her enjoyment and fulfillment in life activities.

NURSING ACTIVITIES:

1. Encourage woman to express feelings related to cancer/surgery with friends, family and partner.
2. Encourage woman to utilize family strengths and resources.
3. Encourage open communication with health professionals.
4. Counsel pt. about overall coping skills.
5. Encourage pt. to identify and participate in enjoyable activities.
6. Discuss employment-related concerns in regard to cancer diagnosis or surgery.
7. Encourage woman to contact the appropriate professional/spiritual advisor for support if quality of life issues are beyond the scope of the nurse.
8. Encourage communication re body image.
9. Refer pt to appropriate community support groups.

EXPECTED OUTCOMES:

1. Pt. will verbalize/demonstrate participation in enjoyable activities.
2. Pt. will verbalize/demonstrate effective communication with family, partner, HCP, and psychological/spiritual advisor.
3. Pt. will verbalize/demonstrate effective coping skills.
4. Pt. will verbalize acceptance of body image after surgical intervention.

QUALITY OF LIFE PROBLEMS

| | |
|---|--------|
| ICD for QOL | V62.89 |
| ICD code consultation - surgeon reports | V65.8 |
| ICD code for Knowledge deficit | V62.3 |
| ICD code for insomnia | 307.41 |

Choose from the following list for Quality of Life Problem statements.

| Problem Statement (Nsg Dx) | Problem Code |
|--|--------------|
| *1. Alteration in quality of life - physical | 2471 |
| *2. Alteration in quality of life - partner | 2473 |
| *3. Alteration in quality of life - social/family | 2476 |
| *4. Alteration in quality of life - emotional | 2472 |
| *5. Alteration in quality of life - physician | 2475 |
| *6. Alteration in quality of life - functional ADLs | 2471 |
| *7. Alteration in quality of life - sexual/body image/risk BC | 2477 |
| 8. Knowledge deficit - community resources | 2148 |
| 9. Role performance altered | 2480 |
| 10. Sleep disturbance, insomnia | 2680 |
| 11. Coping other | 1640 |
| 12. Social isolation | 2710 |
| 13. Social support inadequate | 2720 |
| 14. Knowledge deficit - treatment options | 2228 |
| 15. Consultation - report to doctor | 1585 |
| 16. Knowledge deficit - Disease process cancer | 2180 |

Goal Target in days = 1-14

Goal: Demonstrate or verbalize progress toward pre-surgical QOL level.

Example evaluation Statements: QOL improving per pt statements
QOL remains major concern to pt
QOL returned to pre-surgical level

QUALITY OF LIFE INTERVENTIONS

Assess

*Quality of Life ASSES _3381
Body image ASSES _1180
Altered role performance ... ASSES _3503

Counsel

Altered role performance .. COUNS _3505
Situational COUNS _3535
Support re active listening . COUNS _1010
*Support re individual COUNS _3694
Support re lifestyle changes COUNS _2690
Support re ego enhancement,
 self esteem COUNS _1800
Support re hope instillation COUNS _2400
Support communication among
 family COUNS _1990
Support re coping
 enhancement COUNS _1520
Support re problem solving COUNS _3290
Support re mutual
 goal setting COUNS _2930
Sexual counseling COUNS _3530
Support re body image
 enhancement COUNS _1190
Support group COUNS _3690

Teach

Family therapeutic
 communication TEACH _1990
Coping skills TEACH _1540

Refer

Counselor REFER _5070
Spiritual REFER _5345
*Support group REFER _5355

Consult

Health care provider CONS _2280

Evaluation

*Quality of Life EVAL _3382

ROM, FINE MOTOR ABILITY, SENSATION, LYMPHEDEMA, BSE - OVERVIEW

DEFINITION: Range of Motion (ROM) - any body action involving the muscles, joints, and natural directional movements, such as abduction, extension, flexion, pronation, and rotation.

DEFINITION: Fine Motor Ability - The maximum amount of movement (based on the degree of a circle) which healthy hand and finger joints are capable of.

DEFINITION: Sensation - A feeling, impression, or awareness of a bodily state or condition that results from the stimulation of a sensory receptor site and transmission of the nerve impulse along an afferent fiber to the brain.

DEFINITION: Lymphedema - A secondary disorder characterized by the accumulation of lymph in soft tissue and swelling, caused by removal of lymph channels.

DEFINITION: Breast Self Exam (BSE) - A process in which the breasts and tail of spence are observed and palpated in assessing the presence of changes or abnormalities that could indicate malignant disease.

NURSING ACTIVITIES:

1. Teach patient to perform light ADL's per surgeon guidelines, and encourage pt. to gradually increase arm activity.
2. Teach ROM exercises according to American Cancer Society guidelines.
3. Use pain medication as needed to allow exercise without pain hindrance
4. Assess for signs of nerve and/or circulation impairment in affected arm.
5. Assess for tightness in chest wall.
6. Assess fine motor ability of affected hand.
7. Teach function of lymph system and prevention of lymphedema, including arm elevation, avoidance of pressure, prevention of infection, and exercise/massage.
8. Teach BSE according to American Cancer Society guidelines.

EXPECTED OUTCOMES:

1. ROM in affected shoulder will be adequate to allow pt. to receive adjuvant radiation therapy and perform ADLs.
2. Patient will demonstrate ROM exercises correctly to extent possible: 1. not at all - 0°, 2. very little - 45°, 3. about half - 90°, near full - 135°, full - 180°.
3. Patient will use pain medication to facilitate ROM exercise when necessary.
4. Patient will be free of nerve and/or circulation impairment in affected arm.
5. Patient will be free of tightness in chest wall that interferes with movement or causes pain. Anomalies will be reported to surgeon for treatment.
6. Patient will recover pre-surgical fine motor ability. Anomalies will be reported to surgeon for treatment.
7. Patient will verbalize understanding of the implications of lymph node removal, including lymphedema and increased risk of infection in affected arm.
8. Patient will demonstrate arm elevation/fist squeezing technique to alleviate lymphedema
9. Patient will verbalize understanding or demonstrate BSE according to American Cancer Society guidelines.

EDUCATION

(ROM, FINE MOTOR ABILITY, SENSATION, LYMPHEDEMA, BSE PROBLEMS)

| | |
|---|-------|
| ICD Code for ROM | V49.1 |
| ICD Code for Fine motor ability | 354.9 |
| ICD Code for Sensation, altered, arm | 723.4 |
| ICD Code for Sensation, altered, chest wall | 353.8 |
| ICD Code for Knowledge deficit | V62.3 |
| ICD Code for Consultation - surgeon reports | V65.8 |

Choose from the following list for ROM, fine motor ability, sensation, lymphedema and BSE
Problem statements.

| Problem Statement (Nsg Dx) | Problem Code |
|---|--------------|
| 1. Knowledge deficit, surgery (for lymphedema r/t axillary node dissection) | 2250 |
| 2. Knowledge deficit, s/s infection (r/t lymph node dissection) | 2222 |
| *3. Knowledge deficit, r/t BSE | 2155 |
| *4. Knowledge deficit, r/t lymphedema prevention | 2224 |
| *5. Knowledge deficit, ROM exercises - affected arm | 2146 |
| 6. Knowledge deficit, tx options | 2260 |
| 7. Mobility impaired, r/t coordination | 2290 |
| 8. Mobility impaired, r/t ROM exercise | |
| 9. Mobility impaired, other | 2300 |
| 10. Peripheral neuropathy, side effects | 2450 |
| 11. Weakness | 2860 |
| 12. Pain: Chest wall (intercostal) neuropathy | 2420 |
| 13. Consultation - report to doctor | 1585 |

Goal Target in days = 1-14

- Goals:**
1. ROM in affected shoulder will return to pre-surgical level.
 2. Patient will be free of nerve and/or circulation impairment in affected arm.
 3. Patient will be free of tightness in chest wall that interferes with movement or causes pain.
 4. Patient will recover pre-surgical fine motor ability.
 5. Patient will verbalize understanding of the lymphedema prevention.
 6. Patient will verbalize understanding or demonstrate BSE according to American Cancer Society guidelines.

Example Evaluation Statements:

- ROM WNL for early post-op.
- Pt. demonstrates BSE correctly.
- Pt. verbalizes understanding of effects of node removal

EDUCATION - INTERVENTIONS

(ROM, FINE MOTOR ABILITY, SENSATION, LYMPHEDEMA, BSE)

Assess

Exercise/ROM ASSES _1830
 Functional level ASSES _2180

Prescribe

Exercise/ROM PRESC _1850
 OTC meds PRESC _3120

Teach

*Ex/ROM TEACH _1870
 Prevention of complications TEACH _3280
 Problem solving of side
 effects TEACH _3300
 Functional level TEACH _2210
 *Give educational materials TEACH _2220
 *Lymphedema prevention . TEACH _2725
 *Self breast exam TEACH _1207
 Options and choices (videos) TEACH _3055
 Treatment, surgery TEACH _3830

Skill

Exercise/ROM SKILL _1860

Evaluate

*Exercise/ROM EVAL _1840
 *Functional level (arm) EVAL _2190
 Self breast exam EVAL _1204
 *Lymphedema knowledge ... EVAL _2727

Demonstrate

*ROM arm DEMO _9020
 Self breast exam DEMO _9000

Monitor

Functional level MONIT _2200

Report

S&S lymphedema to surg. REPORT _8020

A Subacute Care Intervention for Short-Stay Breast Cancer Surgery

POST-SURGICAL INTERVIEW
Appendix N

*A Subacute Care Intervention
for
Short-Stay Breast Cancer Surgery*

September 15, 1996 to September 14, 2000

Post-Intervention Questionnaire

Funded by

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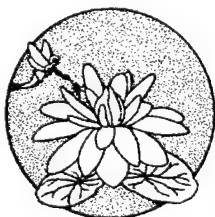
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Charles Given, PhD
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Associate Chair for Research
Family Practice



A New Beginning

*Michigan State University
East Lansing, Michigan 48824*

Information from Screening/Enrollment Form

1. Name of patient: _____
2. Address of patient _____

3. Telephone _____
4. Group
Intervention ____ OR Control ____

Attempts to contact patients (date and time)

| Date | Time | Date | Time | Date | Time |
|-------|-------|-------|-------|-------|-------|
| _____ | _____ | _____ | _____ | _____ | _____ |
| _____ | _____ | _____ | _____ | _____ | _____ |

INTRODUCTION:

Hello. May I speak with Mrs. _____?

Hello, Mrs. _____. My name is _____ and I'm calling from Michigan State University for the Nursing Care for Breast Cancer Study - the study you agreed to participate in just prior to your breast cancer surgery.

1. Do you remember hearing about the study? ☐ Yes (go to 2)
☐ No (refer to **fact sheet**)
☐ Don't know (refer to **fact sheet**)
☐ Refuse/NA (refer to **fact sheet**)

2. We would like to interview you about your progress since surgery. Are you still willing to participate? ☐ Yes (go to 4)
☐ No (go to 3)

3. Would you be willing to let us know what your reasons are? _____

Thank you for your time. (END)

4. The interview will take approximately 45 minutes, which can be divided into a couple of sessions if that's easier for you. We'd like to conduct it within the next week and it must be done before any chemotherapy or radiation is started. Has your doctor recommended chemotherapy or radiation treatments?

- ☐ Yes
☐ Chemotherapy (Go to 4a & 4b)
☐ Radiation (Go to 4a & 4b)
☐ No (Go to 5)

- 4a. Have you made a decision about getting this treatment?

- ☐ Yes, getting chemotherapy. (On what date will this begin? ____/____/____)
☐ Yes, getting radiation. (On what date will this begin? ____/____/____)
☐ Yes, getting both chemotherapy and radiation.
(On what date will chemotherapy begin? ____/____/____)
(On what date will radiation begin? ____/____/____)
☐ Will not get either treatment.
☐ Undecided. (Go to 5)

- 4b. How did you come to this decision? (Please describe) _____

5. Has your doctor recommended any further surgeries, procedures, or medications for treatment of your breast cancer?
____ Yes (Go to 5a - 5c)
____ No (Go to 6)
____ Don't know (Go to 6)

5a. What is the surgery, procedure, or medication? (Please Describe) _____

- 5b. Are you going to have the surgery, procedure, or medication?
____ Yes (On what date? ____/____/____)
____ No
____ Undecided

5c. How did you come to this decision? (Please Describe) _____

6. Do you have time to do part or all of the interview now? ____ Yes (Go to 7)
____ No (Go to 6a & 6b)

6a. I can call you any time Monday through Friday between 9:00 and 5:00 OR if a weekend or evening would be better for you, that would be possible to arrange.

Interview scheduled for: Day _____

Date ____/____/____

Time _____ am
pm

6b. Thank you. I'll talk with you on _____. (END)

7. Before we begin today, I would like to remind you that participation in this interview is voluntary. You are free to withdraw from the study or decline to answer any of the questions. The information you provide to us will be kept in strict confidence and will not be associated with your name, or identify you in any report of the findings of this study. I'd like to ask you some questions about your recovery since surgery, and about how you're feeling. I also have some questions about your medical treatment and any extra expenses you've had since your surgery. The purpose of this interview is learn what women need most after breast cancer surgery.

Do you have any questions before we begin?

- ____ Yes (write in) _____
____ No questions

IF TAPING, ask:

Would you mind if I tape this interview? It is only for purposes of assuring the quality with which I conduct this interview and will be completely confidential.

____ Permission for taping **granted**
____ Permission for taping **denied**

8. To begin with, what was the date and time that you were **admitted** to the hospital for your breast cancer surgery?

Date: ____/____/____ Time: ____ a.m. ____ p.m.

9. What was the date and time that you were **discharged** from the hospital after your breast cancer surgery?

Date: ____/____/____ Time: ____ a.m. ____ p.m.

10. What type of surgery did you have?

____ Lumpectomy with axillary node removal
____ Mastectomy with axillary node removal
____ Axillary node removal
____ Simple Mastectomy
____ Lumpectomy

11. On which side did you have surgery?

____ Right
____ Left
____ Both

12. What is the name of your surgeon? _____ Name

13. In what city is your surgeon located? _____ City

14. When did you first learn about your diagnosis? ____/____/____ Date

Sociodemographic Information for Breast Cancer Patient

1. What is your birth date?
____/____/____
Month / Day/ Year
____ Refused/NA
2. What is your highest level of education completed? (check one)
 - ____ No formal education
 - ____ Completed grade school
 - ____ Completed some high school
 - ____ Completed high school
 - ____ Completed some college or technical training
 - ____ Completed college
 - ____ Completed graduate/professional degree
(post baccalaureate degree)
 - ____ Refused/NA
3. What is your race or ethnic background?
 - ____ Caucasian/White
 - ____ African American/Black
 - ____ Hispanic/Chicano/Mexican American
 - ____ Asian/Pacific Islander
 - ____ Middle Eastern
 - ____ Native American/Alaskan
 - ____ Other (specify: _____)
 - ____ Refused/NA
4. What is your spiritual preference?
 - ____ Protestant
 - ____ Catholic
 - ____ Jewish
 - ____ Buddhist
 - ____ Hindu
 - ____ Muslim
 - ____ Other (specify: _____)
 - ____ None

5. What is your marital status? ☐ Never married
☐ Married
☐ Divorced/separate
☐ Widowed
☐ Refused/NA

Now I am going to ask you questions about who lives with you, and about people who might help you.

6. Do you live alone or with a spouse or significant other? (check all that apply)
☐ Lives alone (go to 10)
☐ Spouse/significant other (go to 7)
☐ None of the above (go to 7)
☐ Refused/NA (go to 7)
7. Do any children live with you? ☐ Yes (go to 7a)
☐ No (go to 8)
☐ Refused/NA (go to 8)

[Interviewer: if has step-children, include in the count of "your children"]

7a. In your household, how many of **your** children are under 13 years of age? ____
☐ Refused/NA

7b. In your household, how many of **your** children are 13 to 17 years of age? ____
☐ Refused/NA

7c. In your household, how many of **your** children are 18 years of age or older? ____
☐ Refused/NA

8. Are there any adult relatives (18 years of age or older) who live with you?
☐ Yes (go to 8a)
☐ No (go to 9)
☐ Refused/NA (go to 9)

8a. How many adult relatives live with you? ____

9. Are there any other **UNRELATED** adults (18 or older) who live with you?
☐ Yes (go to 9a)
☐ No (go to 10)
☐ Refused/NA (go to 10)

9a. How many unrelated adults live with you? ____

10. Is there someone who lives with you or visits on a regular basis and helps with care of any type, including bathing, dressing, cooking, housekeeping or medications?

____ Yes (go to 10a)
____ No (go to next section)
____ Refused/NA (go to next section)

[Interviewer: If answer is "Yes, ____ helps me", ask "Is there anyone else who helps you?" and mark the appropriate spaces in 10a.]

- 10a. Who helps you? (Indicate relationship to patient, including step-children, e.g., if a daughter is helping her mother, check daughter.)

[Interviewer: Mark all answers that apply]

____ Husband
____ Daughter
____ Son
____ Daughter-in-law
____ Son-in-law
____ Sister/sister-in-law
____ Brother/brother-in-law
____ Mother
____ father
____ aunt
____ uncle
____ niece
____ nephew
____ granddaughter
____ grandson
____ other (please specify: _____)
____ Refused/NA

PATIENT SYMPTOM EXPERIENCE

Now I'd like to read a list of symptoms associated with breast cancer surgery, like pain and nausea. Answer YES if you've had any of these symptoms in the past two weeks. [Interviewer: If answer is "No worse than before surgery", mark "No" as the answer.]

| | | | | (Leave any category blank in columns B & C if symptoms not experienced) | | | | | | | | | | |
|----------|---|---|----|---|---|-----------------|---------------|------------|--|------------------------|-----------------------|------------------------|--------------------------------|-------------|
| SYMPTOMS | | A. Have you experienced _____ in the past two weeks? (Mark the appropriate box) | | | B. (IF YES): How severe was this symptom for you? Mild, Moderate, or Severe? (If can't rate severity, mark "1") | | | | C. To what extent did this symptom limit your regular daily activities? No extent, Small extent, Some extent, Great extent, or Very great extent? (Mark the appropriate box) | | | | | |
| | | YES Go to B&C | NO | Ref/ NA | Mild (1) | Moderate (2) | Severe (3) | Ref/ NA | No extent (1) | Small extent (2) | Some extent (3) | Great extent (4) | Very great extent (5) | Ref/ N/A |
| 1 | Nausea | | | | | | | | | | | | | |
| 2 | Pain | | | | | | | | | | | | | |
| 3 | Trouble sleeping | | | | | | | | | | | | | |
| 4 | Fatigue (feel tired) | | | | | | | | | | | | | |
| 5 | Difficulty breathing/sob | | | | | | | | | | | | | |
| 6 | Diarrhea | | | | | | | | | | | | | |
| 7 | Coordination problems with the surgical arm | | | | | | | | | | | | | |
| 8 | Vomiting | | | | | | | | | | | | | |
| 9 | Difficulty concentrating | | | | | | | | | | | | | |
| 10 | Weakness | | | | | | | | | | | | | |
| 11 | Dizziness | | | | | | | | | | | | | |
| 12 | Numbness, tingling, loss of feeling in arm on surgical side | | | | | | | | | | | | | |
| 13 | Poor appetite | | | | | | | | | | | | | |
| 14 | Weight loss | | | | | | | | | | | | | |
| 15 | Fever | | | | | | | | | | | | | |
| 16 | Constipation | | | | | | | | | | | | | |
| 17 | Itching (incision or arm on surgical side) | | | | | | | | | | | | | |
| 18 | Breast tenderness (non-surgical side) | | | | | | | | | | | | | |
| 19 | Lack of sexual interest | | | | | | | | | | | | | |
| 20 | Mood changes | | | | | | | | | | | | | |
| 21 | Limitations in arm movement on the surgical side | | | | | | | | | | | | | |

FUNCTIONAL STATUS

INSTRUMENTAL ACTIVITIES OF DAILY LIVING FOR THE PATIENT

The next set of questions are about activities you might do during a typical day. I'd like you to rate how well you could do these activities before surgery, and then rate how well you can do these activities today. I will give choices for each symptom.

| ACTIVITIES | | BEFORE SURGERY, were you limited in: (Go to questions 1-24) | | | | CURRENTLY, are you limited in this area? | | | |
|------------|---|--|-----------------------|--------------------|--------|--|-----------------------|--------------------|--------|
| | | No, not limited at all | Yes, limited a little | Yes, limited a lot | Ref/NA | No, not limited at all | Yes, limited a little | Yes, limited a lot | Ref/NA |
| 1 | Moderate activities, such as moving a table, bowling or playing golf? <i>Your choices are:</i> | | | | | | | | |
| 2 | Vigorous activities, such as lifting heavy objects or participating in aerobic exercises? | | | | | | | | |
| 3 | Lifting or carrying groceries? | | | | | | | | |
| 4 | Climbing one flight of stairs? | | | | | | | | |
| 5 | Climbing several flights of stairs? | | | | | | | | |
| 6 | Bending, kneeling or stooping? | | | | | | | | |
| 7 | Walking one block? | | | | | | | | |
| 8 | Walking several blocks? | | | | | | | | |
| 9 | Walking one-half mile? | | | | | | | | |
| 10 | Walking more than a mile? | | | | | | | | |
| 11 | Pushing heavy objects? | | | | | | | | |
| 12 | Lifting objects under 10 pounds? | | | | | | | | |
| 13 | Lifting objects over 10 pounds? | | | | | | | | |
| 14 | Writing or handling small objects (with the hand on your surgical side)? | | | | | | | | |
| 15 | Standing in place for 15 minutes or longer? | | | | | | | | |
| 16 | Sitting for long periods (at least one hour)? | | | | | | | | |
| 17 | Brushing or combing your hair (with the hand on the surgical side)? | | | | | | | | |

Date / /
 ID INIT

| ACTIVITIES | | BEFORE SURGERY, were you limited in: (Go to questions 1-24) | | | | CURRENTLY, are you limited in this area? | | | |
|------------|---|--|-----------------------------|--------------------------|--------|--|--------------------------|--------------------------|--------|
| | | No, not limited at all | Yes, limited a little | Yes, limited a lot | Ref/NA | No, not limited at all | Yes, limited a little | Yes, limited a lot | Ref/NA |
| 18 | Putting on a tight-necked sweater or blouse? | | | | | | | | |
| 19 | Pulling up pants or pantyhose? | | | | | | | | |
| 20 | Zippering up a back zipper of a dress? | | | | | | | | |
| 21 | Washing upper part of your back (with the hand on your surgical side)? | | | | | | | | |
| 22 | Reaching into a cupboard over head (with the hand on your surgical side)? | | | | | | | | |
| 23 | Making a double bed? | | | | | | | | |

WOUND HEALING

Now I have some questions about your recovery after surgery. For the first few questions, think about how your incision looked, generally, over the past **four weeks**. Do not take into consideration the first three days you were home after the surgery.

During any period of time over the past 4 weeks, except the first 3 days **immediately** after surgery:

[Interviewer: Repeat this intro as needed for the next four questions]

- | | |
|---|---|
| <p>1a. Did your incision look extremely red?</p> <p><input type="checkbox"/> Yes (go to 1b)</p> <p><input type="checkbox"/> No (go to 2a)</p> <p><input type="checkbox"/> Refused to answer (go to 2a)</p> | <p>1b. During which week(s) was this the most red? (check all that apply)</p> <p><input type="checkbox"/> Week one</p> <p><input type="checkbox"/> Week two</p> <p><input type="checkbox"/> Week three</p> <p><input type="checkbox"/> Week four</p> |
| <p>2a. Was your incision very swollen?</p> <p><input type="checkbox"/> Yes (go to 2b)</p> <p><input type="checkbox"/> No (go to 3a)</p> <p><input type="checkbox"/> Refused to answer (go to 3a)</p> | <p>2b. During which week(s) was this the most swollen? (check all that apply)</p> <p><input type="checkbox"/> Week one</p> <p><input type="checkbox"/> Week two</p> <p><input type="checkbox"/> Week three</p> <p><input type="checkbox"/> Week four</p> |
| <p>3a. Was your incision area extremely tender?</p> <p><input type="checkbox"/> Yes (go to 3b)</p> <p><input type="checkbox"/> No (go to 4a)</p> <p><input type="checkbox"/> Refused to answer (go to 4a)</p> | <p>3b. During which week(s) was this the most tender? (check all that apply)</p> <p><input type="checkbox"/> Week one</p> <p><input type="checkbox"/> Week two</p> <p><input type="checkbox"/> Week three</p> <p><input type="checkbox"/> Week four</p> |
| <p>4a. Was there any pus-like drainage from your incision area?</p> <p><input type="checkbox"/> Yes (go to 4b)</p> <p><input type="checkbox"/> No (go to 5)</p> <p><input type="checkbox"/> Refused to answer (go to 5)</p> | <p>4b. During which week(s) was this the most noticeable? (check all that apply)</p> <p><input type="checkbox"/> Week one</p> <p><input type="checkbox"/> Week two</p> <p><input type="checkbox"/> Week three</p> <p><input type="checkbox"/> Week four</p> |
| <p>5a. Have you taken an antibiotic since your surgery ?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Refused to answer</p> | <p>5b. Did you take an antibiotic to prevent infection or to treat an infection?</p> <p><input type="checkbox"/> Prevent</p> <p><input type="checkbox"/> Treat</p> |

The next few questions are about your surgical incision and surgical drain.

6. Did you have a dressing over your surgical incision?
 ___ Yes (go to 6a)
 ___ No (go to 7)
 ___ Refused/NA (go to 7)
- 6a. How many days did you have a dressing over your incision? Days
 ___ Refused/NA
- 6b. In the past four weeks, were you able to change the dressing over the incision yourself?
 ___ Yes (go to 6c)
 ___ No (go to 6c)
 ___ Didn't change the dressing (go to 7)
 ___ Refused/NA (go to 6c)
- 6c. Did someone help you change the dressing over your incision?
 ___ Yes (go to 6d)
 ___ No (go to 7)
 ___ Refused/ NA (go to 7)
- 6d. Who helped you? (Check all that apply) ___ Unpaid family
 ___ Unpaid friends/others
 ___ Unpaid professional (study nurse)
 ___ Paid family member
 ___ Paid friends/others
 ___ Paid professional
 ___ Refused/NA (go to 7)
- 6e. About how many times did someone else help you change the dressing over your incision?
 Number of times
- 6f. How many minutes did it take someone else to change the dressing each time?
 Number of minutes
7. Did you have a surgical drain? ___ Yes (go to 7a)
 ___ No (go to 11)
 ___ Refused/NA (go to 11)
- 7a. How many days did you have your drain before the doctor removed it? (If two drains, document the longest amount of time a drain was left in the surgical site)
 ___ 1 or 2 days
 ___ 3 or 4 days
 ___ 5 to 10 days
 ___ More than 10 days
 ___ Refused/NA - (go to 11)

- 7b. Did you have a dressing over your drain? ☐ Yes (go to 7c)
☐ No (go to 8)
☐ Refused/NA (go to 8)
- 7c. How many days did you have a dressing over your drain? Days
☐ Refused/NA
- 7d. Were you able to change the dressing over the drain yourself?
☐ Yes (go to 7e)
☐ No (go to 7e)
☐ Didn't change the dressing (go to 8)
☐ Refused/NA (go to 7e)
- 7e. Did someone help you change the dressing over your drain?
☐ Yes (go to 7f)
☐ No (go to 8)
☐ Refused/NA (go to 8)
- 7f. Who helped you? (Check all that apply) ☐ Unpaid family
☐ Unpaid friends/others
☐ Unpaid professional (study nurse)
☐ Paid family member
☐ Paid friends/others
☐ Paid professional
☐ Refused/NA (go to 8)
- 7g. About how many times did someone else help you change the dressing over your drain?
Number of times
- 7h. How many minutes did it take someone else to change the dressing each time?
Number of minutes
8. Were you able to **empty** the drain yourself?
☐ Yes (go to 8a)
☐ No (go to 8a)
☐ Refused/NA (go to 8a)
- 8a. Did anyone help you **empty** the drain?
☐ Yes (go to 8b)
☐ No (go to 9)
☐ Refused/NA (go to 9)
- 8b. Who helped you? (Check all that apply) ☐ Unpaid family
☐ Unpaid friends/others
☐ Unpaid professional (study nurse)
☐ Paid family member
☐ Paid friends/others
☐ Paid professional
☐ Refused/NA (go to 9)
- 8c. How many times did someone help you **empty** the drain? Number of times

- 8d. How many minutes did it take each time for someone else to **empty** the drain?
Number of minutes _____
9. Were you able to **measure and record** the amount of drainage from the drain?
____ Yes (go to 9a)
____ No (go to 9a)
____ Refused/ NA (go to 9a)
- 9a. Did someone else help you measure and record the amount of drainage?
____ Yes (go to 9b)
____ No (go to 10)
____ Refused/ NA (go to 10)
- 9b. Who helped you? (Check all that apply) ____ Unpaid family
____ Unpaid friends/others
____ Unpaid professional (study nurse)
____ Paid family member
____ Paid friends/others
____ Paid professional
____ Refused/NA (go to 10)
- 9c. How many times did someone else help you measure and record the amount of drainage?
Number of times _____
- 9d. About how many minutes did it take each time for someone else to help you measure and record the amount of drainage?
Number of minutes _____
10. Did your tubing get clogged while you had the drain? ____ Yes (go to 10a)
____ No (go to 11)
____ Refused/NA (go to 11)
- 10a. Were you able to unclog the tubing attached to the drain? ____ Yes (go to 10b)
____ No (go to 10b)
____ Refused/NA (go to 10b)
- 10b. Did someone help you milk the tube connected to the drain to unclog it?
____ Yes (go to 10c)
____ No (go to 11)
____ Refused/NA (go to 11)
- 10c. Who helped you? (Check all that apply) ____ Unpaid family
____ Unpaid friends/others
____ Unpaid professional (study nurse)
____ Paid family member
____ Paid friends/others
____ Paid professional
____ Refused/NA (go to 11)

- 10d. About how many times did someone else milk the tube connected to the drain?
Number of times _____
- 10e. How many minutes did it take each time for someone else to milk the tube connected to the drain?
Number of minutes _____
11. Did your surgeon withdraw any fluid from your surgical site by lancing the site or aspirating it with a needle?
____ Yes
____ No
____ Refused/NA
12. Did your surgeon monitor swelling at the surgical site which diminished on its own and did not require drainage?
____ Yes
____ No
____ Refused/NA
13. Did you have your drain re-inserted because fluid accumulated at your surgical site?
____ Yes
____ No
____ Refused/NA
14. Now think about how your arm and chest or breast area where you had surgery have **generally** felt during the past two weeks. Have you had any of the following sensations? (Check all that apply)
- ____ Pain
 - ____ Pins & needles (or tingling)
 - ____ Numbness
 - ____ Weakness
 - ____ Tightness
 - ____ Heaviness
 - ____ Increased skin sensitivity
 - ____ Decreased skin sensitivity
 - ____ Itching
 - ____ Twinges
 - ____ Feeling like the breast tissue is still there
 - ____ None of the above
 - ____ Refused/NA
15. Did your surgery involve removal of the entire breast?
____ Yes
____ No
____ Refused/NA

The next few questions are about exercises you may have done to maintain the range of motion in your arms.

16. Did someone teach you exercises to maintain the range of motion in your arm?
 ___ Yes (go to 16a)
 ___ No (go to 17)
 ___ Refused/NA (go to 17)
- 16a. Who taught you? (Check all that apply)
 ___ Unpaid family
 ___ Unpaid friends/others
 ___ Unpaid professional (study nurse)
 ___ Paid family member
 ___ Paid friends/others
 ___ Paid professional
 ___ Refused/NA
- 16b. About how many times did someone teach you exercises to maintain the range of motion in your arm?
 Number of times ____
- 16c. About how many minutes did it take each time for someone to teach you how to maintain the range of motion in your arm?
 Number of minutes ____
17. Did you do the recommended post-surgical arm exercises?
 ___ Yes (go to 17a)
 ___ No ["Would you like me to send you some information on these exercises?"] (go to 18)
 ___ Refused/NA (go to 18)
- 17a. Did you start arm exercises before or after your drain was removed?
 ___ Before
 ___ After
 ___ Don't know
 ___ Refused/NA
18. Now I'd like you to tell me how high you can raise each arm. I'll read a list of positions and you tell me which one best describes the full extent you can raise your arm **today**. You may want to try these positions as I read them. First, how far can you lift your **right** arm in front of you with the elbow straight?
 Your choices are:
 ___ Not at all (go to 18b)
 ___ Lift it slightly so it looks like you're pointing at something on the ground in front of you. (go to 18a)
 ___ Lift it straight out in front of you. (go to 18a)
 ___ Lift it so it looks like you're pointing at something in the sky. (go to 18a)
 ___ Lift it straight up above your head. (go to 18a)
 ___ Refused/NA (go to 19)

- 18a. Did you have difficulty lifting your arm to any of the previously mentioned positions?
____ Yes (go to 18b)
____ No (go to 19)
____ Refused/ NA (go to 19)
- 18b. Was the difficulty in moving your arm due to a feeling of tightness or due to pain?
____ Tightness
____ Pain
____ Both
____ Neither
____ Refused/NA
19. How far can you lift your left arm in front of you with the elbow straight?
Your choices are:
____ Not at all (go to 19b)
____ Lift it slightly so it looks like you're pointing at something on the ground in front of you.(go to 19a)
____ Lift it straight out in front of you.(go to 19a)
____ Lift it so it looks like you're pointing at something in the sky.(go to 19a)
____ Lift it straight up above your head.(go to 19a)
____ Refused/NA (go to 20)
- 19a. Did you have difficulty lifting your arm to any of the previously mentioned positions?
____ Yes (go to 19b)
____ No (go to 20)
____ Refused/NA go to 20)
- 19b. Was the difficulty in moving your arm due to a feeling of tightness or due to pain?
____ Tightness
____ Pain
____ Both
____ Neither
____ Refused/NA
20. Did you have lymph nodes under your arm removed during your surgery?
____ Yes (go to 20a)
____ No (go to 21)
____ Don't know (go to 20a)
____ Refused/NA (go to 21)
- 20a. The next few questions are about the prevention of lymphedema or swelling of the surgical arm. First, did someone teach you ways to prevent lymphedema?
[Interviewer: Lymphedema prevention includes: protecting the skin from burns and breaks, avoiding pressure on the arm, and doing exercises to promote lymph drainage.]
____ Yes (go to 20b)
____ No ["Would you like me to send you some information on this?"] (go to 21)
____ Refused/NA (go to 21)

- 20b. Who taught you? (Check all that apply) ☐ Unpaid family
☐ Unpaid friends/others
☐ Unpaid professional (study nurse)
☐ Paid family member
☐ Paid friends/others
☐ Paid professional
☐ Refused/NA
- 20c. Since your surgery about how many times did someone teach you ways to prevent lymphedema (swelling of the surgical arm)? Number of times ____
- 20d. About how many minutes did it take each time for someone else to teach you ways to prevent lymphedema? Number of minutes ____
21. Now I'd like to ask you a few questions about your hand on the side of the body where you had your surgery. Before surgery, were you able to pick up a nickle with this hand?
☐ Yes
☐ No
☐ Refused/NA
22. Are you NOW able to pick up a nickle?
☐ Yes
☐ No
☐ Refused/NA
23. Before surgery, were you able to touch your thumb to each finger?
☐ Yes
☐ No
☐ Refused/NA
24. Are you NOW able to touch your thumb to each finger?
☐ Yes
☐ No
☐ Refused to answer

I now have some questions to ask you about breast self exams.

1. Do you know how to do a breast self exam?
☐ Yes (go to 1a)
☐ No [Interviewer ask: "Would you like us to send you some information on this?"] (go to 2)
☐ Refused to answer (go to 2)
- 1a. Do you use the pads of your fingers to cover the entire area of the breast?
☐ Yes
☐ No
☐ Refused/NA

- 1b. Do you examine the area of the breast that extends under your arm? ☐ Yes
☐ No
☐ Refused/NA
- 1c. Do you check for any lumps or thickening? ☐ Yes
☐ No
☐ Refused/NA
- 1d. Do you do breast self exams at the same time each month? ☐ Yes
☐ No
☐ Refused/NA
2. Did you have any lessons to help you learn the Breast Self-Exam since surgery?
☐ Yes (go to 2a)
☐ No (go to next section)
☐ Refused/NA (go to next section)
- 2a. Who helped you? (Check all that apply) ☐ Unpaid family
☐ Unpaid friends/others
☐ Unpaid professional (study nurse)
☐ Paid family member
☐ Paid friends/others
☐ Paid professional
☐ Refused/NA
- 2b. Since your surgery about how many lessons did you have to learn the Breast Self-Exam?
Number of times ____
- 2c. About how many minutes was each lesson? Number of minutes ____

QUALITY OF LIFE QUESTIONNAIRE

Next I'm going to ask you about your physical, social, and overall wellbeing or wellness. Each of these categories should become clear to you as we go through the questionnaire. I will read a list of statements for each category that other women with breast cancer have said are important. Please indicate how each statement pertains to you during the past seven days.

Let's begin. The first six statements will refer to your PHYSICAL WELLNESS. Please indicate how true each statement has been for you during the past seven days.

[Interviewer: Read the five word answer choices for each statement rather than asking to rate on a 1 - 5 scale. Repeat choices as needed - approximately every 3 questions]

The first statement is:

- | | | not
at all | a little
bit | some-
what | quite
a bit | very
much |
|----|---|---------------|-----------------|---------------|----------------|--------------|
| 1. | I have a lack of energy..... <i>The choices are:</i> | 0 | 1 | 2 | 3 | 4 |
| 2. | I have nausea..... | 0 | 1 | 2 | 3 | 4 |
| 3. | Because of my physical condition, I have trouble meeting the needs of my family..... | 0 | 1 | 2 | 3 | 4 |
| 4. | I have pain..... | 0 | 1 | 2 | 3 | 4 |
| 5. | I feel sick..... | 0 | 1 | 2 | 3 | 4 |
| 6. | I am forced to spend time in bed..... | 0 | 1 | 2 | 3 | 4 |
| 7. | Considering the six statements you just replied to (which dealt with lack of energy, nausea, meeting the needs of your family, pain, feeling sick, and spending time in bed), how much would you say your PHYSICAL WELLNESS affects your quality of life? Please rate it on a scale of 0 to 10 in which 0 equals "not at all" and 10 equals "very much so". | | | | | |

0 1 2 3 4 5 6 7 8 9 10

Not at all

Very much so

[Interviewer: "quality of life" may also be referred to as "satisfaction with life"]

Now I am going to read eight SOCIAL statements. Again, please rate how true each statement has been for you during the past seven days.

- | | | not
at all | a little
bit | some-
what | quite
a bit | very
much |
|-----|--|--|-----------------|---------------|----------------|--------------|
| 8. | I feel distant from my friends..... <i>Your choices are:</i> | 0 | 1 | 2 | 3 | 4 |
| 9. | I get emotional support from my family..... | 0 | 1 | 2 | 3 | 4 |
| 10. | I get support from my friends and neighbors..... | 0 | 1 | 2 | 3 | 4 |
| 11. | My family has accepted my illness..... | 0 | 1 | 2 | 3 | 4 |
| 12. | Family communication about my illness is poor..... | 0 | 1 | 2 | 3 | 4 |
| 13. | I feel close to my partner (or my main support person)... | 0 | 1 | 2 | 3 | 4 |
| 14. | Have you been sexually active during the past year?..... | <input type="checkbox"/> Yes (go to 14a) <input type="checkbox"/> No (go to 14a) <input type="checkbox"/> Refused/NA go to 15) | | | | |

14a. On a scale of 0 to 4, where 0 is NOT satisfied and 4 is VERY satisfied, how satisfied are you with your sex life..... 0 1 2 3 4
Not Satisfied *Very Satisfied* ☐ Refused/NA

15. Considering the eight statements you just responded to (which dealt with feeling distant from friends, getting emotional support from family/friends/and neighbors, family accepting your illness, communication about your illness, feeling close to your partner, being sexually active, and feeling satisfied with your sex life), how much would you say your SOCIAL AND FAMILY WELLNESS affects your quality of life? Please rate on a scale of 0 to 10 in which 0 equals "not at all" and 10 equals "very much so."

0 1 2 3 4 5 6 7 8 9 10
Not at all *Very much so*

Next, I am now going to read two statements related to your RELATIONSHIP WITH YOUR DOCTORS. Please indicate how true each statement has been for you during the past seven days. [Note: If the woman asks which doctor, say "Think in general of the doctors you have seen for your breast cancer diagnosis."]

- | | | not
at all | a little
bit | some-
what | quite
a bit | very
much | | | | | | |
|-----|--|---------------|-----------------|---------------|----------------|--------------|---|---|---|---|---|----|
| 16. | I have confidence in my doctors..... <i>The choices are:</i> | 0 | 1 | 2 | 3 | 4 | | | | | | |
| 17. | My doctors are available to answer my questions..... | 0 | 1 | 2 | 3 | 4 | | | | | | |
| 18. | Considering the previous two statements (about having confidence in your doctors and your doctors being available to answer questions), how much would you say your RELATIONSHIP WITH YOUR DOCTORS affects your quality of life? Please rate it on a scale of 0 to 10 in which 0 equals "not at all" and 10 equals "very much so." | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |

Not at all Very much so

Next, I am going to read six statements about feelings. Please indicate how true each statement has been for you during the past seven days.

| | | not at all | a little bit | some- what | quite a bit | very much |
|-----|--|---------------|-----------------|---------------|----------------|--------------|
| 19. | I feel sad..... <i>The choices are:</i> | 0 | 1 | 2 | 3 | 4 |
| 20. | I am proud of how I'm coping with my illness..... | 0 | 1 | 2 | 3 | 4 |
| 21. | I am losing hope in the fight against my illness..... | 0 | 1 | 2 | 3 | 4 |
| 22. | I feel nervous..... | 0 | 1 | 2 | 3 | 4 |
| 23. | I worry about dying..... | 0 | 1 | 2 | 3 | 4 |
| 24. | I worry that my condition will get worse..... | 0 | 1 | 2 | 3 | 4 |
| 25. | Considering the previous six statements (which dealt with feeling sad, coping with the illness, losing hope, feeling nervous, and worrying about dying or that condition will get worse), how much would you say your EMOTIONAL WELLNESS affects your quality of life? Please rate on a scale of 0 to 10 in which 0 equals "not at all," and 10 equals "very much so." | | | | | |

0 1 2 3 4 5 6 7 8 9 10
Not at all *Very much so*

I am now going to read seven statements related to your OVERALL WELLNESS. Please indicate how true each statement has been for you during the past seven days.

| | | not at all | a little bit | some- what | quite a bit | very much |
|-----|---|---------------|-----------------|---------------|----------------|--------------|
| 26. | I am able to work at home..... <i>The choices are:</i> ... | 0 | 1 | 2 | 3 | 4 |
| 27. | My work at home is fulfilling..... | 0 | 1 | 2 | 3 | 4 |
| 28. | I am able to enjoy life..... | 0 | 1 | 2 | 3 | 4 |
| 29. | I have accepted my illness..... | 0 | 1 | 2 | 3 | 4 |
| 30. | I am sleeping well..... | 0 | 1 | 2 | 3 | 4 |
| 31. | I am enjoying the things I usually do for fun..... | 0 | 1 | 2 | 3 | 4 |
| 32. | I am content with the quality of my life right now..... | 0 | 1 | 2 | 3 | 4 |
| 33. | Considering the seven statements you just responded to (which dealt with being able to work at home, finding work at home fulfilling, enjoying life, accepting the illness, sleeping well, enjoying things you usually do for fun, and being content with quality of life right now), how much would you say these general areas affect your quality of life? Please rate it on a scale of 0 to 10 in which 0 equals "not at all" and 10 equals "very much so." | | | | | |

0 1 2 3 4 5 6 7 8 9 10
Not at all *Very much so*

I have seven more statements to read that are related to ADDITIONAL CONCERNS you may have encountered. Please indicate how true each statement has been for you during the past seven days.

| | | not at all | a little bit | some- what | quite a bit | very much |
|-----|---|---------------|-----------------|---------------|----------------|--------------|
| 34. | I have been short of breath..... <i>Your choices are:</i> | 0 | 1 | 2 | 3 | 4 |
| 35. | I am self-conscious about the way I dress..... | 0 | 1 | 2 | 3 | 4 |
| 36. | I feel sexually attractive..... | 0 | 1 | 2 | 3 | 4 |
| 37. | I worry about the risk of cancer in other family members.. | 0 | 1 | 2 | 3 | 4 |
| 38. | I worry about the effect of stress on my illness..... | 0 | 1 | 2 | 3 | 4 |
| 39. | I am bothered by a change in weight..... | 0 | 1 | 2 | 3 | 4 |
| 40. | I am able to feel like a woman..... | 0 | 1 | 2 | 3 | 4 |
| 41. | Considering the previous seven statements (which dealt with being short of breath, self-conscious about the way you dress, feeling sexually attractive, worrying about the risk of cancer in other family members, worrying about the effect of stress on your illness, being bothered by a change in weight, and being able to feel like a women), how much would you say these ADDITIONAL CONCERNS affect your quality of life? Please rate it on a scale of 0 to 10 in which 0 equals "not at all" and 10 equals "very much so." | | | | | |

0 1 2 3 4 5 6 7 8 9 10
Not at all *Very much so*

ANXIETY QUESTIONNAIRE

In this next section I am going to read some statements which people have used to describe themselves. For the first set of statements, please indicate how you feel **right now at this moment**. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your **PRESENT** feelings best.

[Interviewer: Read word answer choices for each statement rather than asking to rate on a scale of 1 - 5. Circle #5 if no response]

| | not at all | some- what | moderately so | very much so | refused/ no answer |
|---|---------------|---------------|------------------|-----------------|-----------------------|
| 1. I feel calm..... <i>The choices are:</i> | 1 | 2 | 3 | 4 | 5 |
| 2. I feel secure..... | 1 | 2 | 3 | 4 | 5 |
| 3. I am tense..... | 1 | 2 | 3 | 4 | 5 |
| 4. I feel strained..... | 1 | 2 | 3 | 4 | 5 |
| 5. I feel at ease..... | 1 | 2 | 3 | 4 | 5 |
| 6. I feel upset..... | 1 | 2 | 3 | 4 | 5 |
| 7. I am presently worrying over possible misfortunes..... | 1 | 2 | 3 | 4 | 5 |
| 8. I feel satisfied..... | 1 | 2 | 3 | 4 | 5 |
| 9. I feel frightened..... | 1 | 2 | 3 | 4 | 5 |
| 10. I feel comfortable..... | 1 | 2 | 3 | 4 | 5 |
| 11. I feel self-confident..... | 1 | 2 | 3 | 4 | 5 |
| 12. I feel nervous..... | 1 | 2 | 3 | 4 | 5 |
| 13. I am jittery..... | 1 | 2 | 3 | 4 | 5 |
| 14. I feel indecisive..... | 1 | 2 | 3 | 4 | 5 |
| 15. I am relaxed..... | 1 | 2 | 3 | 4 | 5 |
| 16. I feel content..... | 1 | 2 | 3 | 4 | 5 |
| 17. I am worried..... | 1 | 2 | 3 | 4 | 5 |
| 18. I feel confused..... | 1 | 2 | 3 | 4 | 5 |
| 19. I feel steady (emotionally)..... | 1 | 2 | 3 | 4 | 5 |
| 20. I feel pleasant..... | 1 | 2 | 3 | 4 | 5 |

ANXIETY QUESTIONNAIRE (Part Two)

Now, I am going to read some more statements which people have used to describe themselves. This time, please indicate how you *generally* feel, rather than how you feel right now. Again, there are no right or wrong answers.

[Interviewer: Read word answer choices for each statement rather than asking to rate on a scale of 1 - 5]

| | almost never | some- times | often | almost always | Refused/ NA |
|---|-----------------|----------------|-------|------------------|----------------|
| 21. I feel pleasant..... <i>Your choices are:</i> | 1 | 2 | 3 | 4 | 5 |
| 22. I feel nervous and restless..... | 1 | 2 | 3 | 4 | 5 |
| 23. I feel satisfied with myself..... | 1 | 2 | 3 | 4 | 5 |
| 24. I wish I could be as happy as others seem to be..... | 1 | 2 | 3 | 4 | 5 |
| 25. I feel like a failure..... | 1 | 2 | 3 | 4 | 5 |
| 26. I feel rested..... | 1 | 2 | 3 | 4 | 5 |
| 27. I am "calm, cool, and collected"..... | 1 | 2 | 3 | 4 | 5 |
| 28. I feel that difficulties are piling up so that I cannot overcome them..... | 1 | 2 | 3 | 4 | 5 |
| 29. I worry too much over something that really doesn't matter..... | 1 | 2 | 3 | 4 | 5 |
| 30. I am happy..... | 1 | 2 | 3 | 4 | 5 |
| 31. I have disturbing thoughts..... | 1 | 2 | 3 | 4 | 5 |
| 32. I lack self-confidence..... | 1 | 2 | 3 | 4 | 5 |
| 33. I feel secure..... | 1 | 2 | 3 | 4 | 5 |
| 34. I make decisions easily..... | 1 | 2 | 3 | 4 | 5 |
| 35. I feel inadequate..... | 1 | 2 | 3 | 4 | 5 |
| 36. I am content..... | 1 | 2 | 3 | 4 | 5 |
| 37. Some unimportant thought runs through my mind and bothers me..... | 1 | 2 | 3 | 4 | 5 |
| 38. I take disappointments so keenly that I can't put them out of my mind..... | 1 | 2 | 3 | 4 | 5 |
| 39. I am a steady person (emotionally)..... | 1 | 2 | 3 | 4 | 5 |
| 40. I get in a state of tension or turmoil as I think over my recent concerns and interests..... | 1 | 2 | 3 | 4 | 5 |

OUT OF POCKET EXPENSES COMPLEMENTARY THERAPIES

Now I'd like to ask you about any other types of therapy that you may have used since surgery to treat your cancer. You may not be familiar with all of these therapies, and many are not covered by health insurance. We would like to know if you use any complementary therapies and about how much you are spending for them.

[Interviewer: If woman says that does not use complementary therapies at all, ask if she minds if you read through the list of questions since some that the public considers mainstream may actually be considered complementary by our study]

1. Have you had a **chiropractic** treatment? __ Yes (go to 1a)
__ No (go to 2)
__ Refused to answer (go to 2)

- 1a. How many treatments since surgery? _____
 1b. How much have you spent in the last four weeks? \$ _____

2. Have you used **hypnosis** as a treatment? __ Yes (go to 2a)
__ No (go to 3)
__ Refused to answer (go to 3)

- 2a. How many treatments since surgery? _____
 2b. How much have you spent in the last four weeks? \$ _____

3. Have you used **yoga** therapy as a way to relax? __ Yes (go to 3a)
__ No (go to 4)
__ Refused to answer (go to 4)

- 3a. How many sessions since surgery? _____
 3b. How much have you spent in the last four weeks? \$ _____

4. Have you had a **massage** treatment? __ Yes (go to 4a)
__ No (go to 5)
__ Refused to answer (go to 5)

- 4a. How many treatments since surgery? _____
 4b. How much have you spent in the last four weeks? \$ _____

5. Have you had an **acupuncture** treatment?

- ☐ Yes (go to 5a)
☐ No (go to 6)
☐ Refused to answer (go to 6)

5a. How many treatments since surgery? _____

5b. How much have you spent in the last four weeks? \$ _____

6. Have you been to a **therapeutic spa** or **retreat** for treatment of your cancer?

- ☐ Yes (go to 6a)
☐ No (go to 7)
☐ Refused to answer (go to 7)

6a. How many treatments since surgery? _____

6b. How much have you spent in the last four weeks? \$ _____

6c. Please briefly describe your treatment _____

7. Have you had a **therapeutic touch** treatment?

- ☐ Yes (go to 7a)
☐ No (go to 8)
☐ Refused to answer (go to 8)

7a. How many treatments since surgery? _____

7b. How much have you spent in the last four weeks? \$ _____

8. Have you had **biofeedback** treatments?

- ☐ Yes (go to 8a)
☐ No (go to 9)
☐ Refused to answer (go to 9)

8a. How many treatments since surgery? _____

8b. How much have you spent in the last four weeks? \$ _____

9. Have you had a **guided imagery** session?

- ☐ Yes (go to 9a)
☐ No (go to 10)
☐ Refused to answer (go to 10)

9a. How many sessions since surgery? _____

9b. How much have you spent in the last four weeks? \$ _____

9c. Please briefly describe your treatment _____

10. Do you receive **spiritual healing** treatments?

- ☐ Yes (go to 10a)
☐ No (go to 11)
☐ Refused to answer (go to 11)

10a. How many treatments since surgery? _____

10b. How much have you spent in the last four weeks? \$ _____

10c. Please briefly describe your treatment _____

11. Do you practice any special **cultural** therapies for your cancer recovery?

- ☐ Yes (go to 11a)
☐ No (go to 12)
☐ Refused to answer (12)

11a. How many treatments since surgery? _____

11b. How much have you spent in the last four weeks? \$ _____

11c. Please briefly describe your treatment _____

12. Do you use **homeopathic** remedies?

- ☐ Yes (go to 12a)
☐ No (go to 13)
☐ Refused to answer (go to 13)

12a. How many times have you used homeopathic remedies since surgery? _____

12b. How much have you spent in the last four weeks? \$ _____

12c. Please briefly describe your treatment _____

13. Have you tried **medications** that are not currently available in the United States?

- ☐ Yes (go to 13a)
☐ No (go to 14)
☐ Refused to answer (go to 14)

13a. How many different kinds of these medications have you taken since surgery? _____

13b. How much have you spent in the last four weeks? \$ _____

13c. Please briefly describe your treatment _____

14. Are you taking **vitamins**, other than a daily multivitamin, that are not covered by health insurance?
- __ Yes (go to 14a)
__ No (go to 15)
__ Refused to answer (go to 15)

- 14a. How many different types of these vitamins have you taken since surgery? ____
- 14b. How much have you spent in the last four weeks? \$ ____
- 14c. Please briefly describe your treatment ____

15. Have you purchased and used **audio** tapes to help you relax?
- __ Yes (go to 15a)
__ No (go to 16)
__ Refused to answer (go to 16)

- 15a. How many of these tapes have you purchased since surgery? ____
- 15b. How much have you spent in the last four weeks? \$ ____
- 15c. Please briefly describe your treatment ____

16. Have you purchased and used **video** tapes to help you relax?
- __ Yes (go to 16a)
__ No (go to 17)
__ Refused to answer (go to 17)

- 16a. How many of these tapes have you purchased since surgery? ____
- 16b. How much have you spent in the last four weeks? \$ ____
- 16c. Please briefly describe your treatment ____

17. Have you received advice about a special cancer diet recommended by someone whose knowledge you trust on nutrition?
- __ Yes (go to 17a)
__ No (go to 18)
__ Refused to answer (go to 18)

- 17a. How many times have you visited your advisor since surgery? ____
- 17b. How much have you spent in the last four weeks? \$ ____
- 17c. Please briefly describe your treatment ____

19. I am now going to read some statements about why people may use complementary therapies. Please tell me how much you agree with each statement.

| | Strongly Disagree | Disagree | Uncertain | Agree | Strongly Agree |
|---|-------------------|----------|-----------|-------|----------------|
| 19a. Complementary therapies may help individuals manage their recovery from surgery. <i>Your choices are:</i> | 1 | 2 | 3 | 4 | 5 |
| 19b. I feel complementary therapies may increase an individual's participation in their recovery. | 1 | 2 | 3 | 4 | 5 |
| 19c. I believe complementary therapies may help cure my cancer. | 1 | 2 | 3 | 4 | 5 |
| 19d. I don't know if complementary therapies can cure my cancer but I will try treatments that seem reasonable. | 1 | 2 | 3 | 4 | 5 |
| 19e. I believe complementary therapies will improve my quality of life. | 1 | 2 | 3 | 4 | 5 |

(5) Other

____ Yes (please describe) _____

[Was there a co-pay and, if so, how much was each payment?]

☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1

____ No _____ Visit 2

____ Don't know _____ Visit 3

____ Refused/NA _____ Visit 4

(6) Out-of-Pocket

____ Yes (What was the total amount spent? _____)

____ No

____ Don't know

____ Refused/NA

LABORATORY:

6. Since your surgery, have you visited a **laboratory** for tests? (check one)

____ Yes (Go to 6a)

____ No (Go to 8 - Primary Care/ Family Doctor)

____ Refused/NA(Go to 8 - Primary Care/ Family Doctor)

[Interviewer: If patient needs more information, read "For example, did you visit a lab for blood tests since your surgery?"

6a. What is the name of the laboratory? (write in)

Name: _____

6b. In which city is this laboratory located? (write in)

City: _____

6c. Excluding other stops, from the time you leave home until you return home, how long does a typical visit take including travel and office time? (write in) Hours _____

6d. For what reasons did you visit this laboratory? (Please Describe) _____

6e. Since your surgery, how many times have you visited a laboratory for tests? (write in) Times _____

6f. On how many visits did someone go with you? (write in) Times _____

7. How did you pay for this laboratory service? Did you pay ... (check all that apply)

(1) Private insurance

____ Yes [Was there a co-pay and, if so, how much was each payment?]

____ No co-pay ____ Co-pay ____ Don't know: \$ _____ Visit 1

____ No _____ Visit 2

____ Don't know _____ Visit 3

____ Refused/NA _____ Visit 4

- ☐ Yes (What was the total amount spent? _____)
☐ No
☐ Don't know
☐ Refused/NA

PRIMARY CARE PHYSICIAN OR FAMILY DOCTOR:

8. Since your surgery, have you visited your primary care physician or family doctor?

- ☐ Yes (Go to 8a)
☐ No (Go to 10 - Emergency Rm/ Urgent Care)
☐ Refused/NA (Go to 10 - Emergency Rm/ Urgent Care)

8a. What is the name of your primary physician or family doctor?

Name: _____

8b. In which city is your primary physician or family doctor located?

City: _____

8c. Excluding other stops, from the time you leave home until you return home,

how long did a typical visit take including travel and office time? (write in) Hours _____

8d. For what reasons did you visit? (check all that apply)

- ☐ Because of problems due to my breast cancer
☐ Because of other health problems
☐ Other (please describe _____)
☐ Refused/NA

8e. Since your surgery, how many times did you visit your primary care physician or family doctor?

(write in) Times _____

8f. On how many visits did someone go with you?

(write in) Times _____

9. How did you pay for this primary care physician or family doctor service? Did you pay ... (check all that apply)

(1) Private insurance

- ☐ Yes [Was there a co-pay and, if so, how much was each payment?]
☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1
☐ No _____ Visit 2
☐ Don't know _____ Visit 3
☐ Refused/NA _____ Visit 4

(2) Medicare

____ Yes [Was there a co-pay and, if so, how much was each payment?]
 ☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1
 ____ No _____ Visit 2
 ____ Don't know _____ Visit 3
 ____ Refused/NA _____ Visit 4

(3) Medicaid

____ Yes [Was there a co-pay and, if so, how much was each payment?] Visit 1
 ☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 2
 ____ No _____ Visit 3
 ____ Don't know _____ Visit 4
 ____ Refused/NA _____

(4) **Service is free**

☐ Yes
☐ No
☐ Don't know
☐ Refused/NA

(5) Other

____ Yes (please describe) _____
 [Was there a co-pay and, if so, how much was each payment?]
 ☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1
 ____ No _____ Visit 2
 ____ Don't know _____ Visit 3
 ____ Refused/NA _____ Visit 4

(6) Out-of-Pocket

☐ Yes (What was the total amount spent? _____)
☐ No
☐ Don't know
☐ Refused/NA

EMERGENCY DEPARTMENTS OR URGENT CARE CENTERS:

10. Since your surgery, how many **different emergency departments or urgent care centers** did you visit?

__ 0 (go to 13 - Hospitals)

__ 1 __ 2 __ 3 __ 4 or more (go to 10a)

__ Refused/NA (go to 13 - Hospitals)

10a. What was the name of this emergency department or urgent care center? (write in)

Name: _____

10b. In what city is this emergency department or urgent care center located? (write in)

City: _____

10c. Excluding time for other stops, how long does it take you to reach this emergency department or urgent care center?
(write in) _____ Minutes

10d. Since your surgery, on how many different occasions did you visit this emergency department or urgent care center?

__ 1 __ 2 __ 3 or more __ Refused/NA

10e. For what reasons were you admitted to this emergency department or urgent care center the first time? (check all that apply)

__ Because of problems due to my breast cancer surgery

__ Because of other health problems

__ Other (please describe) _____

__ Refused/NA

10f. How many times did someone go with you? (write in) Times _____

[Interviewer: If admitted to this ER/UCC for a 2nd time --- go to 10g,

If no second admissions to this ER/UCC but admitted to another ER/UCC --- go to 11,

If no other admissions to this ER/UCC or any other ER/UCC --- go to 12]

10g. For what reasons were you admitted to this emergency department or urgent care center the second time? (check all that apply)

- ☐ Because of problems due to my breast cancer surgery
☐ Because of other health problems
☐ Other (please describe) _____
☐ Refused/NA

10h. How many times did someone go with you?

(write in) Times _____ (If not admitted to a 2nd ER/UCC -- Go to 12)

11. Now, for the **second** emergency department or urgent care center which you visited since your surgery, what was the name of this emergency department or urgent care center? (write in)

Name: _____

11a. In what city was this emergency department or urgent care center located? (write in)

City _____

11b. Excluding time for other stops, how long did it take you to reach this emergency department or urgent care center?
(write in) _____ Minutes

11c. Since your surgery, on how many different occasions did you visit this emergency department or urgent care center?
(write in) Times _____

11d. For what reasons did you visit this emergency department or urgent care center? (check all that apply)

- ☐ Because of problems due to my breast cancer surgery
☐ Because of other health problems
☐ Other (please describe) _____
☐ Refused/NA

12. How did you pay for this emergency room/urgent care center service? Did you pay ... (check all that apply)

(1) Private insurance

Yes [Was there a co-pay and, if so, how much was each payment?] Visit 1
 ☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 2
 No _____ Visit 3
 Don't know _____ Visit 4
 Refused/NA _____

(2) Medicare

Yes [Was there a co-pay and, if so, how much was each payment?] Visit 1
 ☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 2
 No _____ Visit 3
 Don't know _____ Visit 4
 Refused/NA _____

(3) Medicaid

___ Yes [Was there a co-pay and, if so, how much was each payment?]
 ☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1
 ___ No _____ Visit 2
 ___ Don't know _____ Visit 3
 ___ Refused/NA _____ Visit 4

(4) Service is free

☐ Yes
☐ No
☐ Don't know
☐ Refused/NA

(5) Other _____

____ Yes (please describe) _____
 [Was there a co-pay and, if so, how much was each payment?]
 ☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1
 ____ No _____ Visit 2
 ____ Don't know _____ Visit 3
 ____ Refused/NA _____ Visit 4

(6) Out-of-Pocket

☐ Yes (What was the total amount spent?) _____
☐ No
☐ Don't know
☐ Refused/NA

HOSPITALS:

13. Since your surgery, into how many **different hospitals** were you admitted?

(write in) Number ____ (if "0", go to 18 - Nursing Home)

13a. What was the name of this hospital? (write in) Name: _____

13b. In what city was this hospital located? (write in) Name: _____

13c. Excluding time for other stops, how long did it take you to reach this hospital?
(write in) _____ Minutes

13d. Since your surgery, on how many different occasions were you admitted to this hospital?
____ one
____ two
____ three or more
____ Refused/NA

13e. For what reasons were you admitted to this hospital the **first time**? (check all that apply)
____ Because of problems due to my breast cancer surgery
____ Because of other health problems
____ Refused/NA

Please describe the problem: (write in) _____

13f. How long were you in this hospital the first time you were admitted? (write in) _____ Hours

13g. How many complete nights did you spend in this hospital? (write in) _____ Nights

13h. How many days did someone stay with you at this hospital? (write in) _____ Days

[Interviewer: If patient had second admission to this hospital, go to question 14;

If patient was admitted to second hospital, go to question 15;

If patient had no other hospital admissions go to question 17.]

14. For what reasons were you admitted the **second time**? (check all that apply)

- ____ Because of problems due to my breast cancer surgery
____ Because of other health problems
____ Refused/NA

Please describe the problem: (write in) _____

14a. How long were you in this hospital the second time you were admitted? (write in) _____ Hours

14b. How many complete nights did you spend in this hospital? (write in) _____ Nights

14c. How many days did someone stay with you at this hospital? (write in) _____ Days

[If patient admitted to a 2nd hospital, go to question 15;

If patient had no other admissions, go to question 17]

15. Now, for the **second** hospital to which you were admitted since your surgery, what was the name of this hospital?
(write in) Name: _____

15a. In which city is this hospital located? City: _____

15b. Excluding time for other stops, how long did it take to get to this hospital? (write in) _____ Minutes

15c. Since your surgery, on how many different occasions were you admitted to this hospital?
(write in) _____ Times

15d. For what reasons were you admitted to this hospital the **first time**? (check all that apply)

- ____ Because of problems due to my breast cancer surgery
____ Because of other health problems
____ Refused/NA

Please describe the problem: (write in) _____

15e. How long were you in this hospital the first time you were admitted? (write in) _____ Hours

15f. How many complete nights did you spend in this hospital? (write in) _____ Nights

15g. How many days did someone stay with you at this hospital? (write in) _____ Days

**[Interviewer: If patient had second admission to second hospital, go to question 16;
If patient had no other admissions, go to question 17.]**

16. For what reasons were you admitted the **second time**? (check all that apply)

____ Because of problems due to my breast cancer surgery

____ Because of other health problems

____ Refused/NA

Please describe the problem: (write in) _____

16a. How long were you in this hospital the first time you were admitted? (write in) _____ Hours

16b. How many complete nights did you spend in this hospital? (write in) _____ Nights

16c. How many days did someone stay with you at this hospital? (write in) _____ Days

17. How did you pay for this hospital service? Did you pay ... (check all that apply)

(1) Private insurance

____ Yes [Was there a co-pay and, if so, how much was each payment?]

____ No co-pay ____ Co-pay ____ Don't know: \$ _____ Visit 1

____ No _____ Visit 2

____ Don't know _____ Visit 3

____ Refused/NA _____ Visit 4

(2) Medicare

____ Yes [Was there a co-pay and, if so, how much was each payment?]

____ No co-pay ____ Co-pay ____ Don't know: \$ _____ Visit 1

____ No _____ Visit 2

____ Don't know _____ Visit 3

____ Refused/NA _____ Visit 4

___ Yes [Was there a co-pay and, if so, how much was each payment?]
 ☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1
 ___ No _____ Visit 2
 ___ Don't know _____ Visit 3
 ___ Refused/NA _____ Visit 4

☐ Yes
☐ No
☐ Don't know
☐ Refused/NA

| | | | | | |
|----------------|------------------------------------|---------------------------------|--------------------------------------|----------|---------|
| | <input type="checkbox"/> No co-pay | <input type="checkbox"/> Co-pay | <input type="checkbox"/> Don't know: | \$ _____ | Visit 1 |
| ___ No | | | | _____ | Visit 2 |
| ___ Don't know | | | | _____ | Visit 3 |
| ___ Refused/NA | | | | _____ | Visit 4 |

☐ Yes (What was the total amount spent?) _____
☐ No
☐ Don't know
☐ Refused/NA

(4) Service is free

- ☐ Yes
☐ No
☐ Don't know
☐ Refused/NA

(5) Other

☐ Yes (please describe) _____

[Was there a co-pay and, if so, how much was each payment?]

☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1

☐ No _____ Visit 2

☐ Don't know _____ Visit 3

☐ Refused/NA _____ Visit 4

(6) Out-of-Pocket

☐ Yes (What was the total amount spent?) _____

☐ No

☐ Don't know

☐ Refused/NA

The next set of questions is about services you may have used during your recovery from breast cancer surgery.

A. SOCIAL WORKER

First I have some questions about services provided by a social worker. A social worker is someone who helps find community resources for patients and provides social support.

1. Have you used a **SOCIAL WORKER** since your breast cancer surgery?

(check one)

- ☐ Yes (Go to 1 a)
☐ No (Go to part B - Home Care Nurse)
☐ Refused/NA (Go to part B)

1a. Since your breast cancer surgery, how often have you used this service? (write in)

Number of times

1b. How helpful was this service to you? Was it ... (check one)

- ☐ Very helpful
☐ Somewhat helpful
☐ Not helpful
☐ Refused/NA

1c. How did you pay for this service? Did you pay ... (check all that apply)

(1) Private insurance

- ☐ Yes [Was there a co-pay and, if so, how much was each payment?]
☐ No co-pay ☐ Co-pay ☐ Don't know: \$ Visit 1
☐ No Visit 2
☐ Don't know Visit 3
☐ Refused/NA Visit 4

(2) Medicare

- ☐ Yes [Was there a co-pay and, if so, how much was each payment?]
☐ No co-pay ☐ Co-pay ☐ Don't know: \$ Visit 1
☐ No Visit 2
☐ Don't know Visit 3
☐ Refused/NA Visit 4

(3) Medicaid

- ☐ Yes [Was there a co-pay and, if so, how much was each payment?]
☐ No co-pay ☐ Co-pay ☐ Don't know: \$ Visit 1
☐ No Visit 2
☐ Don't know Visit 3
☐ Refused/NA Visit 4

(4) Service is free

- ☐ Yes
☐ No
☐ Don't know
☐ Refused/NA

(5) Other

☐ Yes (please describe) _____

[Was there a co-pay and, if so, how much was each payment?]

☐ No co-pay ☐ Co-pay: \$ _____ Visit 1 (write in)

- ☐ No _____ Visit 2
☐ Don't know _____ Visit 3
☐ Refused/NA _____ Visit 4

(6) Out-of-Pocket

☐ Yes (What was the total amount spent? \$ _____)

- ☐ No
☐ Don't know
☐ Refused/NA

B. HOME CARE NURSE

Next, I have some questions about services provided by a Home Care Nurse. A Home Care Nurse is an R.N. provided through an agency who comes to the home to provide skilled nursing care such as dressing changes, help with medication, health promotion education (such as breast self exam technique or lymphedema prevention) or other medical activities. A Home Care Nurse does not usually provide personal care such as bathing.

1. Have you had a **HOME CARE NURSE** since your breast cancer surgery? (check one)

- ___ Yes (Go to 1a)
 ___ No (Go to **part C - Housekeeping Services**)
 ___ Refused/NA (Go to **part C**)

1a. Which Home Care Nurse service did you use? Please choose from the following choices:

[Interviewer: Be sure to read ALL choices]

- ___ Home Care Nurse provided by this breast cancer study (go to **part C**)
 ___ Home Care Nurse **not** provided by the study (go to 1b)
 ___ Both (go to 1b)
 ___ Refused/NA (go to **part C**)

1b. The following few questions refer to a Home Care Nurse service **not** provided by the study. First, how often have you used this service? (write in) Number of visits: _____

1c. How helpful was this service for you? Was it ... (check one)

___ Very helpful
 ___ Somewhat helpful
 ___ Not helpful
 ___ Refused/NA

1d. How did you pay for this service? Did you pay ... (check all that apply)

(1) Private insurance

- ___ Yes [Was there a co-pay and, if so, how much was each payment?]
 ___ No co-pay ___ Co-pay ___ Don't know: \$ _____ Visit 1
 ___ No _____ Visit 2
 ___ Don't know _____ Visit 3
 ___ Refused/NA _____ Visit 4

____ Yes [Was there a co-pay and, if so, how much was each payment?]
 ☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1
 ____ No _____ Visit 2
 ____ Don't know _____ Visit 3
 ____ Refused/NA _____ Visit 4

____ Yes [Was there a co-pay and, if so, how much was each payment?]
 ☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1
 ____ No _____ Visit 2
 ____ Don't know _____ Visit 3
 ____ Refused/NA _____ Visit 4

☐ Yes
☐ No
☐ Don't know
☐ Refused/NA

Yes (please describe) _____
 [Was there a co-pay and, if so, how much was each payment?]
☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1
 No _____ Visit 2
 Don't know _____ Visit 3
 Refused/NA _____ Visit 4

☐ Yes (What was the total amount spent? \$ _____)
☐ No
☐ Don't know
☐ Refused/NA

C. HOUSEKEEPING OR PERSONAL CARE SERVICES

Now I have a few questions about Housekeeping or Personal Care Services.

1. Have you used **HOUSEKEEPING SERVICES** for help with chores such as cleaning, cooking, bathing, or dressing since your breast cancer surgery?

☐ Yes (Go to 1a)
☐ No (Go to **part D- Transportation**)
☐ Refused/NA (Go to **part D**)

1a. Since your breast cancer surgery, how often have you used this service? (write in) Number of times

1b. How helpful was this service for you? Was it ... (check one)

☐ Very helpful
☐ Somewhat helpful
☐ Not helpful
☐ Refused/NA

1c. How did you pay for this service? Did you pay ... (check all that apply)

(1) Private insurance

☐ Yes [Was there a co-pay and, if so, how much was each payment?]
☐ No co-pay ☐ Co-pay ☐ Don't know: \$ Visit 1
☐ No Visit 2
☐ Don't know Visit 3
☐ Refused/NA Visit 4

(2) Medicare

☐ Yes [Was there a co-pay and, if so, how much was each payment?]
☐ No co-pay ☐ Co-pay ☐ Don't know: \$ Visit 1
☐ No Visit 2
☐ Don't know Visit 3
☐ Refused/NA Visit 4

(3) Medicaid

☐ Yes [Was there a co-pay and, if so, how much was each payment?]
☐ No co-pay ☐ Co-pay ☐ Don't know: \$ Visit 1
☐ No Visit 2
☐ Don't know Visit 3
☐ Refused/NA Visit 4

(4) Service is free

☐ Yes
☐ No
☐ Don't know
☐ Refused/NA

(5) Other

____ Yes (please describe) _____

[Was there a co-pay and, if so, how much was each payment?]

☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1

____ No _____ Visit 2

____ Don't know _____ Visit 3

____ Refused/NA _____ Visit 4

(6) Out-of-Pocket

____ Yes (What was the total amount spent? \$ _____)

____ No

____ Don't know

____ Refused/NA

D. TRANSPORTATION SERVICES

The next few questions are about Transportation Services. This is an agency that provides rides to physician's offices, to treatment sessions, or to get medications. This is not public transportation or an informal service provided by a friend or family member.

1. Have you used **TRANSPORTATION SERVICES** since your breast cancer surgery?

- ☐ Yes (Go to 1a)
☐ No (Go to **next section**)
☐ Refused/NA (Go to **next section**)

1a. Since your breast cancer surgery, how often have you used this service? (write in) Number of times

1b. How helpful was this service for you? Was it ... (check one) ☐ Very helpful
☐ Somewhat helpful
☐ Not helpful
☐ Refused/NA

1c. How did you pay for this service? Did you pay ... (check all that apply)

(1) Private insurance

- ☐ Yes [Was there a co-pay and, if so, how much was each payment?]
☐ No co-pay ☐ Co-pay ☐ Don't know: \$ Visit 1
☐ No Visit 2
☐ Don't know Visit 3
☐ Refused/NA Visit 4

(2) Medicare

- ☐ Yes [Was there a co-pay and, if so, how much was each payment?]
☐ No co-pay ☐ Co-pay: ☐ Don't know \$ Visit 1
☐ No Visit 2
☐ Don't know Visit 3
☐ Refused/NA Visit 4

(3) Medicaid

- ☐ Yes [Was there a co-pay and, if so, how much was each payment?]
☐ No co-pay ☐ Co-pay ☐ Don't know: \$ Visit 1
☐ No Visit 2
☐ Don't know Visit 3
☐ Refused/NA Visit 4

(4) Service is free

- ☐ Yes
☐ No
☐ Don't know
☐ Refused/NA

(5) Other

____ Yes (please describe) _____

[Was there a co-pay and, if so, how much was each payment?]

☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1

____ No _____ Visit 2

____ Don't know _____ Visit 3

____ Refused/NA _____ Visit 4

(6) Out-of-Pocket

____ Yes (What was the total amount spent? \$ _____)

____ No

____ Don't know

____ Refused/NA

I now have a few questions about supplies you may have purchased or other expenses incurred during your recovery from breast cancer surgery. Let's begin with medications.

A. MEDICATIONS

1. Since your breast cancer surgery, have you or other family members spent money on **medications** for you because your insurance does not cover medications, you have a co-pay, or because you have exceeded maximums for your insurance? This includes both prescription and over-the-counter medications (check one):

___ Yes (Go to **1a**)
 ___ No (Go to **part B - Special Supplies**)
 ___ Refused/NA (Go to **part B - Special Supplies**)

- 1a. How did you pay for these medications? Did you pay ... (check all that apply)

- (1) Private insurance**

___ Yes [Was there a co-pay and, if so, how much was each payment?]
 ☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1
 ___ No _____ Visit 2
 ___ Don't know _____ Visit 3
 ___ Refused/NA _____ Visit 4

- (2) Medicare

Yes [Was there a co-pay and, if so, how much was each payment?]
☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1
 No _____ Visit 2
 Don't know _____ Visit 3
 Refused/NA _____ Visit 4

- (3) Medicaid

____ Yes [Was there a co-pay and, if so, how much was each payment?]
 ☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1
 ____ No _____ Visit 2
 ____ Don't know _____ Visit 3
 ____ Refused/NA _____ Visit 4

- (4) Service is free

☐ Yes
☐ No
☐ Don't know
☐ Refused/NA

- (5) Other

Yes (please describe) _____
 [Was there a co-pay and, if so, how much was each payment?]
☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1
 No _____ Visit 2
 Don't know _____ Visit 3
 Refused/NA _____ Visit 4

Date ____/____/____
ID ____ INIT ____

(6) Out-of-Pocket

- ☐ Yes (What was the total amount spent? \$_____)
☐ No
☐ Don't know
☐ Refused/NA

B. SPECIAL SUPPLIES

1. Since your breast cancer surgery, have you or other family members spent money on **special supplies** for you because of your illness? For example, dressings for your incision? (check one)

 Yes (Go to 1a)

___ No (Go to part C -Special Foods or Food Supplements)

 Refused/NA (Go to part C - Special Foods or Food Supplements)

- 1a. How did you pay for these special supplies? Did you pay ... (check all that apply)

(1) Private insurance

____ Yes [Was there a co-pay and, if so, how much was each payment?]

☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1

No _____ Visit 2

| | |
|------------|---------|
| Don't know | Visit 3 |
|------------|---------|

| Refused/NA | Visit 4 |
|------------|---------|
|------------|---------|

(2) Medicare

Yes [Was there a co-pay and, if so, how much was each payment?]

☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1

No _____ Visit 2

Don't know Visit 3

| Refused/NA | Visit 4 |
|------------|---------|
| 1 | 1 |
| 2 | 2 |
| 3 | 3 |
| 4 | 4 |
| 5 | 5 |
| 6 | 6 |
| 7 | 7 |
| 8 | 8 |
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| 92 | 92 |
| 93 | 93 |
| 94 | 94 |
| 95 | 95 |
| 96 | 96 |
| 97 | 97 |
| 98 | 98 |
| 99 | 99 |
| 100 | 100 |

(3) Medicaid

Yes [Was there a co-pay and, if so, how much was each payment?]

☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1

No Visit 2

Don't know Visit 3

| Refused/NA | Visit 4 |
|------------|---------|
| | |

(4) Service is free

Yes

No

Don't know

Refused/NA

(5) Other

Yes (please describe)

[Was there a co-pay and, if so, how much was each payment?]

☐ No co-pay ☐ Co-pay ☐ Don't know: \$ _____ Visit 1No Visit 2

Don't know Visit 3

| Refused/NA | Visit 4 |
|------------|---------|
|------------|---------|

(6) Out-of-Pocket

Yes (What was the total amount spent? \$)

No

Don't know

Refused/NA

C. SPECIAL FOODS OR FOOD SUPPLEMENTS

1. Since your breast cancer surgery, have you or other family members spent money on **special foods or food supplements** for you because of your illness, not including home delivered meals? (check one)

___ Yes (Go to 1a)
___ No (Go to **part D - Additional Expenses**)
___ Refused/NA (Go to **part D - Additional Expenses**)

- 1a. What was the total amount spent? \$ _____ (Go to **part D**)
___ Don't know (Go to 1b)
___ Refused/NA (Go to **part D**)

[Interviewer: Record exact amount; if respondent has difficulty estimating, ask for approximation to the nearest \$10.]

- 1b. Was it ... (check one for each until amount is estimated)

(1) More than \$10? (check one) ___ Yes (Go to **1b-2**) ___ No (Go to **D**) ___ Refused/NA (Go to **D**)
(2) More than \$20? (check one) ___ Yes (Go to **1b-3**) ___ No (Go to **D**) ___ Refused/NA (Go to **D**)
(3) More than \$50? (check one) ___ Yes (Go to **1b-4**) ___ No (Go to **D**) ___ Refused/NA (Go to **D**)
(4) More than \$75? (check one) ___ Yes (Go to **1b-5**) ___ No (Go to **D**) ___ Refused/NA (Go to **D**)
(5) If more than \$100, approximately how much was spent? (write in) \$ _____

D. ADDITIONAL EXPENSES

1. What kinds of additional expenses related to your illness have you or other family members had? (For example, increased utility bills, ordering take-out food more than usual, or travel expenses for a relative to come and stay with you.)
(list types of expenses) _____

- 1a. What was the total amount spent? (write in) \$ _____ (Go to part E)
_____ Don't know (Go to 1b)
_____ Refused/NA (Go to part E)

[Interviewer: Record exact amount; if respondent has difficulty estimating, ask for approximation to the nearest \$10.]

1b. Was it ... (check one for each until amount is estimated)

- (1) More than \$10? (check one) __ Yes (Go to 1b-2) __ No (Go to E) __ Refused/NA (Go to E)
(2) More than \$20? (check one) __ Yes (Go to 1b-3) __ No (Go to E) __ Refused/NA (Go to E)
(3) More than \$50? (check one) __ Yes (Go to 1b-4) __ No (Go to E) __ Refused/NA (Go to E)
(4) More than \$75? (check one) __ Yes (Go to 1b-5) __ No (Go to E) __ Refused/NA (Go to E)
(5) If more than \$100, approximately how much was spent? (write in) \$ _____

E. TOTAL OUT-OF-POCKET EXPENSES

1. Since your breast cancer diagnosis, do you know the total out-of-pocket expenses (including co-pays) that was spent? ☐ Yes (Go to 1a)

☐ No (don't know exact amount) (Go to 1b)

☐ Refused/NA (Go to next section)

1a. How much was spent? (write in)

\$ _____ (Go to next section)

☐ Refused/NA (Go to next section)

[Interviewer: Record exact amount; if respondent has difficulty estimating, ask for approximation to the nearest \$10.]

1b. Was it ... (check one for each until amount is estimated)

(1) More than \$20? (check one) ☐ Yes (Go to 1b-2) ☐ No (next section) ☐ Refused/NA (next section)

(2) More than \$50? (check one) ☐ Yes (Go to 1b-3) ☐ No (next section) ☐ Refused/NA (next section)

(3) More than \$100? (check one) ☐ Yes (Go to 1b-4) ☐ No (next section) ☐ Refused/NA (next section)

(4) More than \$200? (check one) ☐ Yes (Go to 1b-5) ☐ No (next section) ☐ Refused/NA (next section)

(5) More than \$300? (check one) ☐ Yes (Go to 1b-6) ☐ No (next section) ☐ Refused/NA (next section)

(6) If more than \$300, approximately how much was spent? (write in) \$ _____

BASIC INCOME AND EMPLOYMENT QUESTIONS

The next several questions are about your basic income and employment. I'll begin with some questions regarding household savings.

1. Since your breast cancer surgery, how much of **your household's savings** (the patient's family) have been spent on care? Please estimate the overall amount. (write in or check one)

\$ (Go to 2)
 Don't know (Go to 1a)
 None (Go to 2)
 Family had no savings (Go to 2)

[Interviewer: Record exact amount; if respondent has difficulty estimating, ask for approximation to the nearest \$10.]

1a. Was it ... (check one for each until amount is estimated)

- (1) More than \$20? (check one) Yes (Go to 1a-2) No (Go to 2) Refused/NA (Go to 2)
 (2) More than \$50? (check one) Yes (Go to 1a-3) No (Go to 2) Refused/NA (Go to 2)
 (3) More than \$100? (check one) Yes (Go to 1a-4) No (Go to 2) Refused/NA (Go to 2)
 (4) More than \$200? (check one) Yes (Go to 1a-5) No (Go to 2) Refused/NA (Go to 2)
 (5) If more than \$300, approximately how much was spent? (write in) \$

2. Since your breast cancer surgery, have you or your family incurred any **new debt**? (check one)

 Yes (Go to 2a)
 No (Go to 3)
 Refused/NA (Go to 3)

2a. How much new debt was incurred? \$ (Go to 3)
 Don't know (Go to 2b)
 Refused/NA (Go to 3)

[Interviewer: Record exact amount; if respondent has difficulty estimating, ask for approximation to the nearest \$10.]

2b. Was it ... (check one for each until amount is estimated)

- (1) More than \$20? (check one) Yes (Go to 2b-2) No (Go to 3) Refused/NA (Go to 3)
 (2) More than \$50? (check one) Yes (Go to 2b-3) No (Go to 3) Refused/NA (Go to 3)
 (3) More than \$100? (check one) Yes (Go to 2b-4) No (Go to 3) Refused/NA (Go to 3)
 (4) More than \$200? (check one) Yes (Go to 2b-5) No (Go to 3) Refused/NA (Go to 3)
 (5) If more than \$300, approximately how much was spent? (write in) \$

3. Can you estimate your combined yearly household income for the last calendar year before deducting taxes?

- ☐ Yes (Go to 3a)
☐ No (Go to 4)
☐ Refused/NA (Go to 4)

3a. Approximately how much was it?

- \$ _____ (Go to 4)
☐ Don't know (Go to 3b)
☐ Refused/NA (Go to 4)

3b. Was it... (check one for each until amount is estimated)

- | | |
|---|---|
| <input type="checkbox"/> below 5 thousand dollars | <input type="checkbox"/> between 35 and 40 thousand dollars |
| <input type="checkbox"/> between 5 and 10 thousand dollars | <input type="checkbox"/> between 40 and 45 thousand dollars |
| <input type="checkbox"/> between 10 and 15 thousand dollars | <input type="checkbox"/> between 45 and 50 thousand dollars |
| <input type="checkbox"/> between 15 and 20 thousand dollars | <input type="checkbox"/> between 50 and 60 thousand dollars |
| <input type="checkbox"/> between 20 and 25 thousand dollars | <input type="checkbox"/> between 60 and 70 thousand dollars |
| <input type="checkbox"/> between 25 and 30 thousand dollars | <input type="checkbox"/> between 70 and 80 thousand dollars |
| <input type="checkbox"/> between 30 and 35 thousand dollars | <input type="checkbox"/> between 80 and 90 thousand dollars |
| | <input type="checkbox"/> 90 thousand and over |

4. Which of the following statements best describes the financial impact that paying for your care has had on you and your family? I will read a list of choices for you. (check one)

- ☐ We have had to cut back sharply on expenses and still can't make ends meet.
☐ We have had to cut back sharply on expenses but have been able to make ends meet.
☐ We have had to do without some things but are getting by.
☐ We have been able to pick up the extra expenses fairly easily.
☐ So far there has been no impact; neither I nor my family have contributed to the costs of my care.
☐ Refused/NA

PATIENT EMPLOYMENT

For the next set of questions I would like to ask about your employment or work.

1. Were you employed before your breast cancer surgery? ☐ Yes (Go to 1a) ☐ No (Go to 2) ☐ Refused/NA (Go to **final section**)

- 1a. Were you employed...(check all that apply) ☐ Full-time ☐ Part-time ☐ Self-employed (☐ Full-time **OR** ☐ Part-time)

1b. What kind of work did you do? _____

1c. What are your most important activities and duties? (write in) (Go to 3)

2. Are you.....
☐ A homemaker (Go to **final section**)
☐ Retired (Go to **final section**)
☐ Other (Go to **final section**)

3. Since your breast cancer surgery, have you returned to your previous employment?
☐ Yes
☐ No
☐ Refused/NA

4. How are you compensated for your work? Are you paid... (check all that apply)
☐ A monthly salary or wage
☐ An hourly wage rate
☐ Piece rates
☐ Commissions
☐ Tips or bonuses
☐ Any other form of compensation?
(Please, describe: _____)
☐ Refused/NA

- 4a. Since your surgery, have you missed days of work **without pay**? (check one) ☐ Yes (Go to 4a: **part 1**) ☐ No (Go to 4b) ☐ Refused/NA (Go to 4b)

If Yes: (1) How many days have you taken without pay? (write in) _____ Days

- (2) Did you lose any wages or salary? (check one) ☐ Yes (Go to **4a: part 3**)
☐ No (Go to **4b**)
☐ Refused/NA (Go to **4b**)

- (3) Approximately how much have you lost in wages or salary, up until today, because you missed work? (write in) \$ _____

- 4b. Are paid vacation, sick, and/or personal days a part of your employment benefits package? (check one)
☐ Yes (Go to **4c**)
☐ No (Go to **5**)
☐ Refused/ NA (Go to **5**)

- 4c. Since your surgery, have you taken **paid sick days**? (check one) ☐ Yes (Go to **4c: part 1**)
☐ No (Go to **4d**)
☐ Refused/NA (go to **4d**)

If Yes: (1) How many paid sick days have you taken? (write in) _____ Days

- 4d. Since your surgery, have you taken **paid personal days**? (check one) ☐ Yes (Go to **4d: part 1**)
☐ No (Go to **4e**)
☐ Refused/NA (Go to **4e**)

If Yes: (1) How many paid personal days have you taken? (write in) _____ Days

- 4e. Since your surgery, have you used up **paid vacation days**? (check one) ☐ Yes (Go to **4e: part 1**)
☐ No (Go to **5**)
☐ Refused/NA (Go to **5**)

If Yes: (1) How many paid vacation days have you taken? (write in) _____ Days .

5. The next few questions deal with changes you may have had in your current work situation. To begin with, have you missed training opportunities since your surgery? (check one) ☐ Yes
☐ No
☐ Refused/NA

- 5a. Since your surgery, has your cancer diagnosis caused you to turn down a new job or promotion? (check one)
☐ Yes
☐ No
☐ Refused/NA

5b. Since your surgery, has your cancer diagnosis changed your work in other ways not mentioned? (check one)

____ Yes (Ask to Describe)

____ No (Go to 6)

____ Refused/NA (Go to 6)

(If yes) Describe: _____

6. Now, we are interested in any **difference** between your **earnings before** your breast cancer surgery and your **current earnings**. Have your earnings changed? (Read choices)

____ Yes - my earnings have decreased (Go to 6a)

____ Yes - my earnings have increased (Go to 6a)

____ No - my earnings have stayed the same

____ Yes - the change has affected me financially in other ways (describe) (Go to 6a)

____ Refused/NA (Go to next section)

6a. We are interested in the difference between your earnings before surgery and your earnings now. Have your annual earnings, monthly earnings, weekly earnings or hourly wage rate changed? (check one)

____ Annual (salary, wages, etc.)

____ Monthly (salary, wages, etc.)

____ Weekly (salary, wages, etc.)

____ Hourly wage rate

____ Refused/NA

6b. By how much have your earnings changed? _____ Amount

6c. When did the change in your earnings occur? (write in) ____/____
Month/Year

We are nearing the end of the interview and I have a few final questions for you regarding future planning of care for women with breast cancer.

BOTH GROUPS:

1. Could you please explain how you might see other women with breast cancer benefitting from the information you've shared with us? (write in) _____

2. Please explain whether or not you feel as though you benefitted from participation in the study. (write in) _____

INTERVENTION GROUP ONLY:

3. Do you feel the nursing care provided by the study had an impact on your recovery? Please explain. (write in) _____

Date ____/____/____
ID ____ INIT ____

Termination of Interview

These are all the questions I have today. I appreciate your time in answering them. Are there any questions or comments you have for me or would like passed on to the study staff? (Interviewer -- if so, write down and try to answer.)

Interviewer: If patient has questions you cannot answer, or are not comfortable answering, please note these and forward them to the Interviewer Coordinator.

Thank you very much for answering these questions. If you have any further questions about the project, please call our study office at 517-432-5511, or if calling long distance, call toll-free at 1-888-432-5511.

Thank you again for your time.

Interviewer: Go to Interviewer Assessment

INTERVIEWER ASSESSMENT

1. Factual questions were answered with: ☐ No difficulty
☐ Some difficult
☐ Great difficulty
2. Subjective questions were answered with: ☐ No difficulty
☐ Some difficulty
☐ Great difficulty
3. What information did the patient seek from you? (check all that apply)
☐ No information
☐ Information about the study
☐ Information about community agencies
☐ Information about breast cancer
☐ Other (please describe: _____)
4. Please write any additional relevant comments or observations you would care to make about this patient's situation.

5. Please comment on patient's health condition and whether it affected her ability to answer questions.

6. Did you have to stop interview because of patient fatigue or health problems? ☐ Yes ☐ No
- Please comment on the number of times you had to stop, etc. _____

7. Interview disposition:
☐ Completed ☐ Unable To contact patient
☐ Patient deceased ☐ Patient moved. (Record the attempts to reach patient: _____)
☐ Patient refused ☐ Patient started interview but was unable to complete interview.
☐ Patient institutionalized

Date for disposition:

- (1) If completed, patient refused, or unable to contact patient, then today's date: ____/____/____
- (2) If patient deceased, then date of death: ____/____/____
- (3) If patient institutionalized, then date of institutionalization: ____/____/____

END